

**Social Support for School-Age Siblings
of Children With Cancer:
A Comparison Between Parent and Sibling Perceptions**

by

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John Stephen Murray

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Abstract

Social Support for School-Age Siblings of Children With Cancer: A Comparison
Between Parent and Sibling Perceptions

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This descriptive, exploratory study investigated the social support interventions received by siblings of children with cancer and which of those interventions are perceived as being helpful. A comparison between the sibling's perceptions and their parents was made. The conceptual framework was guided by House's (1981) work on social support, which posits major categories of support variables including emotional, informational, instrumental, and appraisal support. A nonprobability purposive sample consisted of 50 school-age siblings of children with cancer and their parents. Subjects completed either the parent or sibling version of the Nurse-Sibling Social Support Questionnaire (NSSSQ).

Descriptive statistical analyses were performed to examine NSSSQ helpfulness and frequency scores for both siblings and parents. Paired t-tests were used to test the difference between the responses given by siblings and their parents on the NSSSQ helpfulness and frequency scales. Regression analyses were chosen to determine variables providing the most predictive power for

helpfulness scores of well siblings. A Correlation Coefficient was calculated using the total score from the Personal Attribute Inventory for Children (PAIC) and the total NSSSQ scores for siblings to further explore the validity of the NSSSQ. Finally, using the NSSSQ, content analysis addressed the responses to the open-ended questions at the end of the instruments.

Results demonstrated that siblings perceive interventions aimed at providing emotional and instrumental support the most helpful. Parents perceived interventions aimed at meeting the siblings' need for emotional and informational support the most beneficial. Simple regressions revealed no statistically significant results for any of the predictor variables. The correlation coefficient indicated there was a small correlation between the sibling version of the NSSSQ and the PAIC scale suggesting the NSSSQ is measuring a related, but different construct than the PAIC. Results of the content analysis of the NSSSQ open-ended questions for siblings and parents support the quantitative findings of the NSSSQ. Well siblings reported interventions aimed at meeting their needs for emotional and instrumental support as being more helpful in adjusting to the childhood cancer experience; parents reported more interventions aimed at meeting well sibling needs for emotional and informational support.

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Chapter I

The diagnosis of cancer in any family member can be a devastating experience for the entire family. However, when the family member is a child, the experience is even more traumatic. This announcement disrupts the natural order of life where typically the elderly suffer and die and the young carry on with the work of life (Rollins, 1990). The news of this disease, with all of its uncertainty and uneasiness, would be ample cause for crisis in any family system (Rollins, 1990).

Problem Statement

Cancer is the leading cause of disease-related death among children. An estimated 7,600 new cases of childhood cancer were diagnosed in 1996 (American Cancer Society, 1996). Currently one in every 330 children in the United States develops cancer before the age of 19. Furthermore, the incidence of cancer among children is increasing (National Childhood Cancer Foundation, 1997). Treatment of childhood cancers has progressed rapidly in recent years, with over 60% of children diagnosed expected to survive (Hodson, 1990). Many childhood cancers are now perceived as chronic life-threatening diseases involving repeated hospitalizations and intensive treatments (Cohen, 1985). Despite this progress, each affected family faces years of uncertainty about the eventual outcome, whatever the statistical probability of a cure. The family must learn to integrate the child's illness and treatment into their lives as they strive to

regain a sense of normalcy. Despite the brighter outlook for today's children with cancer, they endure repeated hospitalizations and clinic visits, lengthy courses of rigorous chemotherapy and/or radiation, painful procedures, changes in physical appearance, lack of energy, and frequent absences from school (Cohen, 1985).

The overwhelming demands of this disease, including the prognosis, are unpredictable elements that cause enormous stress for all family members and must be dealt with on a daily basis (Cohen, 1985; Rollins, 1990).

The demands of cancer on children and their parents have been studied and understood for many years now. (Binger et al., 1969; Chesler & Barbarin, 1987; Cobb, 1956; Morrow, Carpenter, & Hoagland, 1984; Murray, 1999a). Little focus has been placed on one other very important part of the family system - the well siblings. In the health care profession today, there is a growing awareness that the psychosocial needs of well siblings of children with cancer are less adequately met than those of other family members (Murray, 1999a).

Throughout the literature on childhood cancer, siblings are often referred to as the forgotten grievers. According to Chesler and Barbarin (1987), siblings are the most left out and unattended to of all family members during the experience of serious childhood illness. Rollins (1990) and Murray (1999a; 2000a) report that siblings are overlooked during the childhood cancer experience, especially at the time of diagnosis. The focus of the health care professionals, family, and friends is on the ill child and parents. In a study by Tritt

and Esses (1988) it was the healthy siblings who were identified as the most unhappy members in one-third of families interviewed who had a chronically ill child. Over one-half of the siblings interviewed believed that the ill child received special treatment. The brothers and sisters of the ill child learn their needs are secondary to those of the ill child (Tritt & Esses, 1988).

Siblings

Traditionally, the primary emphasis in pediatric nursing has been placed on the parent-child dyad. However, today there is increasing recognition of the powerful influence that siblings have on each other. Sibling relationships are often characterized by their intensity, complexity, and ambiguity (Boer & Dunn, 1992; Trahd, 1986). The span of time these relationships encompass is one of the most critical elements that contribute to this intensity and complexity.

Childhood cancer can have damaging effects on the psychosocial well being of the healthy sibling, as well as the relationship between the healthy sibling and ill child (Murray, 2000a). Some of these changes are undoubtedly attributed to the enormous demands of the disease while others are a result of the dynamics of the sibling relationship itself (i.e., age differences, birth order, spacing of children within families, and previous relationships). An enormous potential exists for well siblings to be an incredible source of support, strength, and comfort for each other (Harding, 1996). When confronted with the demands of cancer the sibling bond can become stronger (Rollins, 1990). Nurses, and all health care

providers, should explore ways to take advantage of this bond and use it in a positive and proactive way to enhance family coping and empower the family system (Harding, 1996).

Social Support

One way of improving the psychosocial adaptation of siblings of children with cancer, is through the implementation of social support interventions. There are a number of studies in the literature that address the importance of social support for reducing the psychological distress related to the intense stressors of serious illness such as cancer (Dunkel-Schetter, 1984; Morrow et al., 1984; Taylor, Falke, Shoptaw, & Lichtman, 1986). Social support can be a valuable resource in helping siblings of children with cancer cope with the many psychosocial demands of the childhood cancer experience. There is a paucity of research on the sources of support for families living with chronic illness (Murray, 1999a; Woods, Yates, & Primomo, 1989). However, research on sources of support for siblings in particular, is practically nonexistent (Murray, 1999a, in press a). More emphasis on the use of social support in moderating the adjustment difficulties of siblings is critical. The types of social support identified by Dunkel-Schetter (1984) as being invaluable to patients with cancer (emotional and informational support) should also be utilized in working with siblings of children with cancer. In addition, instrumental and appraisal support should be considered as moderators of stressors in the childhood cancer experience as well. In the same

article, Dunkel-Schetter (1984) points out that support from health care providers is important. Every effort should be made by care providers working in pediatric oncology to employ these types of supports with family members and siblings in particular. Social support as described by House (1981) provides the most comprehensive approach to addressing and understanding the emotional, informational, instrumental, and appraisal needs of siblings of children with cancer.

In summary, advances in pediatric oncology have significantly improved the rate of survival in childhood cancers. As greater advances are made with this disease, understanding the impact not only on the patient, but also on other members of the family is critical. Siblings of childhood cancer patients are considered to be vulnerable to adjustment difficulties. It has been shown that within the family, the needs of the well siblings are met least of all. One way of improving sibling adaptation to this illness experience is with interventions aimed at providing social support.

Social support appears to be beneficial in the positive psychosocial adjustment of patients with cancer and of parents of children with cancer. Siblings of children with cancer often do not receive adequate support during the illness experience. The role of social support in decreasing the demands of the childhood cancer experience can have a positive outcome with siblings of children with cancer as well. Supporting siblings during this potentially traumatic experience

requires not only recognition of the complexity of the illness experience, but also the usefulness of social support interventions (Murray, in press a).

Research Questions

The major research questions for this study were as follows:

- (1) What social support interventions do school-age siblings of children with cancer perceive as being helpful?
- (2) What types of social support interventions do school-age siblings of children with cancer currently receive?
- (3) What social support interventions do parents of school-age siblings of children with cancer perceive as being helpful for their well children?
- (4) What types of social support interventions do parents of school-age siblings of children with cancer think their well children currently receive?
- (5) What are the differences between school-age sibling's and parent's perceptions of social support interventions?
- (6) What variables best predict school-age sibling's perceptions of helpful interventions based on total scores from the NSSSQ?

Purpose of this Study

The purpose of this study was to investigate what social support interventions (emotional, informational, instrumental, appraisal support) siblings of children with cancer currently receive, and what interventions are perceived as being helpful. A comparison between the sibling's perceptions and their parents

was made. The principal investigator has found in clinical practice that parents determine what support programs well siblings participate in. It is possible that programs parents perceive to be supportive may not be helpful from the perspective of the well sibling. To date, no research has investigated siblings' perceptions of support compared with their parents. The limited research done over the past 40 years has identified adjustment difficulties, such as depression, sadness, fear, and feelings of loneliness, in children who have a sibling with cancer (Binger et al., 1969; Cain, Fast, & Erickson, 1964; Cobb, 1956; Kramer, 1981; Murray, 1998, 1999a; Simeon, 1984; Tritt & Esses, 1988; Walker, 1988; Williams, Lorenzo, & Borja, 1993). Included in these studies were recommendations for interventions that could be helpful in reducing the incidence of such outcomes. One of the major goals of this study was to learn more about sibling perceptions of the usefulness of these interventions in clinical practice and to recommend interventions to pediatric health care providers that would be instrumental in meeting the needs of siblings.

Conceptual Framework

Historical Origins. Before the mid-1970s, the philosophical roots of the concept of social support could be found in examples where it was primarily used in a concrete sense to denote a person, relationship, or transaction (Veitel & Baumann, 1992). During the 1980s, authors used the term social support to describe a class of functionally compatible, concrete social interchanges of

resources (Dohrenwend, Dohrenwend, Dodson, & Shrout, 1984). Also, during this time, social support was said to represent a "metaconcept" lacking specificity and definition, rather than a definable and measurable entity (Thomson & Stewart, 1987). The notion of supportive quality, which can be abstracted from particular relationships and transactions and can be used to characterize them, has taken root in the thinking of most researchers today (Veitel & Baumann, 1992).

The development of social support theory came from the considerable controversy that centered on the stress process in the 1970s. Theorists such as Cassell (1976), Cobb (1976), and Kaplan, Cassell, and Gore (1977) argued that supports could act as resistance factors against stress. That is social support reduces, or buffers, the adverse psychological impacts of exposure to negative life events and/or chronic difficulties (Veitel & Baumann, 1992). Research studies confirm this "buffering" view of social support influences (Turner, 1983; Veitel & Baumann, 1992). Other studies (Thoits, 1982; 1983) have argued that lack of social support and changes in support over time are stressors in themselves, and as such ought to have direct influences upon psychological symptomatology, whether or not other stressful circumstances occur. A number of studies conducted during the 1970's and 1980's confirmed the main-effect view of social support influences (Andrews, Tennant, Hewson, & Vaillant, 1978; Aneshensel & Frerichs, 1982; Thoits, 1983; Turner, 1983). These studies reported an inverse association between measures of support and indicators of psychological

disturbance, and no stress-buffering effects at all. One other study reported that social support reduces symptoms directly and reduces the disturbing impacts of stressful circumstances (Dean & Ensel, 1982).

During the past three decades, there has been an explosion in the number of research studies examining the relationship between the occurrence of a wide variety of social stressors and both physical and psychological symptomatology (Veitel & Baumann, 1992). These studies have come from the fields of Sociology, Psychology, Nursing, and Medicine and have come from a variety of perspectives (Murray, in press a). Investigators have focused on reactions to events, such as natural disasters, divorce, job loss, retirement, illness, and bereavement (House, 1981). Another area investigated by researchers concentrated on the accumulated contributions of a variety of life circumstances to both physical and psychological distress (Dohrenwend, 1981). The relatively modest relationship between measures of social stressors and measures of illness behavior has lead many researchers to explore the ways in which a variety of biological, psychological, behavioral, and situational factors might moderate the relationship between life stressors and health outcomes (Johnson & Sarason, 1980). One particular factor, which has received more attention than all others combined, is social support.

Definitions of Social Support. The term social support has been around for many years; however, it has only been used by social scientists for 30 years. Many conceptual definitions of social support have been offered from a number

of different fields. In 1974, Caplan suggested that social support systems consisted of "continuing social aggregates that provide individuals with opportunities for feedback about themselves and for validation of their expectations of others" (p. 4). Cobb (1976) defined social support as "information leading the subject to believe he is cared for and loved, esteemed and valued, and belongs to a network of communication and mutual obligations" (p. 300). House's (1981) multidimensional construct suggests that "social support is an interpersonal transaction involving one or more of the following: (1) emotional support, (2) instrumental aid, (3) information, and (4) appraisal" (p. 39). This conceptualization was chosen for this study because the research literature supports the all-encompassing aspects of social support identified by House (1981). House's (1981) conceptualization holistically captures all constructs of social support where other conceptualizations capture only certain components of social support. Research on siblings of children with cancer has shown that interventions that are critical in facilitating sibling adjustment should be based on meeting their needs for emotional, informational, instrumental, and appraisal support (Cohen, 1985; Havermans & Eiser, 1994; Kramer, 1981; Murray, 1995, 1998; Walker et al., 1992). The Nurse - Sibling Social Support Questionnaire used consists of 30 items assessing sibling and parent perceptions of supportive interventions based on House's (1981) conceptualization of social support. The

instrument includes items measuring the emotional, instrumental, informational, and appraisal components of support.

Despite the diversity of approaches taken to define social support, there exist clear commonalties and differences in orientation. These differences and commonalties are particularly noticeable when one considers operational definitions used. One commonality apparent in the definitions is that social support is frequently considered to be a multidimensional (containing more than one) construct. For example, House's conceptualization contains emotional, instrumental, informational, and appraisal support. Kahn and Antonuci (1980) define social support as interpersonal transactions containing affect (love, liking, respect, and admiration), affirmation (agreement and acknowledgment of appropriateness or rightness of another's behavior), and aid (direct service or giving of material supplies). While some researchers have neglected to reflect this multidimensionality in their measures of support, most researchers involved in the development of social support measures identify and attempt to assess several different categories of support. Some of the category labels which appear in a number of scales include emotional support, esteem support, belonging support, network support, appraisal support, tangible support, instrumental support, and informational support (House, 1981; Veitel & Baumann, 1992).

House's (1981) Conceptualization of Social Support. Social support may function in a stressor-specific fashion. That is social support may reduce, or

moderate, the adverse psychosocial impact of exposure to difficult life events and/or challenges such as the childhood cancer experience. Stressors vary in the types of adaptational demands they can moderate. Social support is effective in minimizing the negative effects of stressors only when there is congruence between adaptational demands and support resources (Cohen & Hoberman, 1983).

In social support theory (House, 1981), support is believed to influence health when psychological stress is experienced and the individual's ability to adapt is seriously taxed or exceeded. The perception of the objective stressors plays a central role in the stress and coping process. According to Lazarus (1980), the resources a person believes are available are arrayed psychologically against the dangers and harms being faced. This is the first stage in the stress and coping process at which social support operates, and researchers speculate this is the point at which social support plays its major role (Gottlieb, 1983; House, 1981).

In 1981, House developed his theory of social support to clarify the nonspecific meaning of social support and to indicate how and why support should or could reduce stress, improve health, or minimize the impact of stressors on health. The result was an extensive conceptualization that included emotional, informational, instrumental, and appraisal support.

Social support, as defined by House (1981), is an interpersonal transaction involving one or more of the following: (a) emotional support, which involves

providing empathy, encouragement, understanding, caring, love, and trust; (b) instrumental support, providing direct help or material aid to help other people do their work, take care of themselves, or help them financially; (c) informational support, providing information or guidance to help a person better understand and adjust to changes in his/her life; and (d) appraisal support pertaining to self evaluation, acknowledging that one's beliefs and interpretations of a situation are appropriate (House, 1981).

Emotional support seems to protect individuals indirectly from the negative consequences of stress by reinforcing their sense of mastery and self-esteem. Presumably, the individual with a strong sense of self (facilitated in part by the presence of emotional support) will be better able to mobilize other coping resources than the person who must also deal with a diminished sense of self (Pearlin, Liberman, Menaghan, & Mullan, 1981). Others have proposed that emotional support may decrease the reactivity of the neuroendocrine system, making the person less physiologically reactive to physiological stress (Henry & Stephens, 1977).

In many situations, the provision of instrumental support (money, task assistance, direct intervention on behalf of the recipient) can lessen the load of coping with the stressor or alter the nature of the stressor itself (such as when the stressor involves a loss of material resources) (House, 1981; Veitel & Baumann, 1992). This type of support involves behaviors that directly help the person in

need. Helping individuals with instrumental behaviors increases their ability to recognize the need for, and accept other forms of support to respond to stressful situations. This is thought to occur when instrumental support decreases that particular stressor (i.e. financial difficulty, change in daily routines) making the individual more receptive to intervention with other forms of support, which help to minimize other possible stressors, and improve coping and adaptation to the stressful life event (House, 1981).

Informational support (advice, directives, or information communicated directly) can facilitate coping by encouraging forms of cognitive or behavioral coping which might increase stress resistance, redirect inappropriate coping activities, and result in the ability to tolerate increased levels of stress (House, 1981). Informational support helps to clarify any misunderstandings individuals may have. The degree to which an individual's informational needs are met influences how well they cope with the illness experience (Spinetta, 1981).

Appraisal support (feedback relevant to self-evaluation through processes such as social comparison) may, like emotional support, result in enhanced self-esteem which can facilitate coping in a number of ways (House, 1981). Appraisal support can help individuals to examine a stressful situation closely and interpret it more appropriately. This will help to dispel any fears and misconceptions they may have.

Researchers have also pointed to several other interpersonal mechanisms which facilitate coping. Interactions which divert one's attention away from the stressor may reduce the magnitude of the stress reaction by distracting the individual's attention from internal sensations of symptomatology (Pennebaker, 1982). Many researchers have focused their attention on what has come to be termed perceived social support, defining the construct in largely cognitive terms while others place more emphasis on the actual nature of interpersonal transactions which reduce stress and enhance coping (House, 1981; Langford, Bowsher, Maloney, & Lillis, 1997; Veitel & Baumann, 1992).

Social Support and Siblings of Children With Cancer. Psychosocial adjustment to the childhood cancer experience has been described as a process of overcoming familial emotional events (Morrow, Hoagland, & Carnrike, 1981). Social support has been viewed as a potentially protective element in dealing with the effects of these stressful events either directly, or because it moderates the effects of stress on individual health and well being (House, 1981).

Over the past two decades, a sizeable number of studies have suggested the importance of social support for moderating the physical and psychological distress related to the severe stressors associated with serious illnesses such as cancer. Cancer, because of its unpredictable nature and lengthy treatment process, is regarded as an ongoing stressor that requires continual physical and

psychological adjustments, not only by the patient but by the family as well (Murray, 1995; Spinetta, 1981).

Social support can be beneficial to siblings of children with cancer in helping them to deal with the psychosocial demands of having a brother or sister with cancer. As the literature demonstrates, social support has been found to be a strong resource for adjusting to stressful illness experiences (Murray, in press a). In 1984, Morrow, Carpenter, and Hoagland studied 107 parents of children with cancer. The purpose of this study was to examine the effects of social support on the psychosocial problems of the family when a child is being treated for cancer. Results of the study showed that social support was related to positive psychosocial adjustment, particularly for parents who had a child currently receiving treatment (Morrow, Carpenter, & Hoagland, 1984).

In another study by Bloom (1982), adult cancer patients identified they had enhanced needs for social support in order to deal with the fears and uncertainties related to their illness. Furthermore, they felt these needs could often be met by such caregivers as physicians and nurses. Morrow, Hoagland, and Carnrike (1981) also found that the psychosocial adjustment of parents of children with cancer was significantly related to parents' perceived support, not only from spouses, but also from relatives, friends, other parents with ill children, and health care providers. La Montagne and Pawlack (1990) studied parents of children in pediatric intensive care units. Findings showed that social support was a

frequently used coping strategy. The authors recommend that clinicians assess who is supportive for the parents and emphasized that ongoing support may be especially important in helping them adjust to the stress of the experience.

Health care professionals can provide high quality social support for families of children with cancer (Ross, 1978). In a study by Dunkel-Schetter (1984), physicians, nurses, and other health care providers were mentioned as sources of support as frequently as family members. Similarly, Morrow, Hoagland, and Morse (1982) found that a large number of parents reported health care professionals as being supportive during their child's illness. Dunkel-Schetter (1984) found that although respondents found family, friends, and caregivers to be helpful in providing support, different types of support were more valuable when received from certain individuals. Cancer patients rated emotional support as being most helpful (81% of respondents) followed by informational support (41% of respondents). The most surprising finding was that emotional support was found to be equally helpful whether it came from family, friends, or health care providers. Furthermore, lack of emotional support from health care providers was seen as unhelpful. Instrumental and appraisal support were rated as less helpful (6% of respondents for each). Informational support was perceived as helpful if it was provided by health care providers, and perceived as unhelpful if it was provided by family and friends (Dunkel-Schetter, 1984).

Social support can be beneficial to siblings of children with cancer by altering the demands of the illness as perceived by the sibling. During the childhood cancer experience, parents contend with the demands of shared allocation of time and energies to ill children and their well siblings (Harding, 1996). More often than not, parents end up spending much more of their time at the hospital with the ill child. When they are at home they are often emotionally and physically tired, worried, and troubled. Eventually the entire family structure becomes disrupted (Harding, 1996). Siblings are often overlooked in the process. Their questions go unanswered, they develop fears and anxieties, and they begin to withdraw from their family and social groups (Harding, 1996; Murray, 2000; Snyder, 1986; Spinetta, 1981; Walker, 1990).

For this study, an explanatory model (Appendix A) was developed by the investigator that lists factors related to adjustment difficulties in siblings of children with cancer based on an extant review of the literature (Murray, 1999a). Previous researchers have identified possible factors that may result in adjustment difficulties in well siblings such as the nature of the disease, developmental level of the child, parental factors, and lack of social support (Cohen, 1985; Iles, 1979; Kramer, 1981; Murray, 2000; Sloper & While, 1996; Wang & Martinson, 1996). Most of the research conducted with well siblings has identified adjustment difficulties such as feelings of loneliness, depression, anger, acting out behaviors, guilt, poor school performance, and low self-esteem and self-worth (Binger et al.,

1969; Cain et al., 1964; Chesler & Barbarin, 1987; Cobb, 1956; Morrow, Carpenter & Hoagland, 1984; Murray, 1995, 1999a; Walker, 1988). In this model, it was hypothesized that by identifying sibling and parent perceptions of supportive interventions, and implementing these interventions in clinical practice, favorable outcomes may include a reduction in the number of adjustment difficulties seen with well siblings and enhanced coping. It is theorized that social support interventions function as a moderator variable.

Definition of Terms

- (1) In this study, social support is defined as an interpersonal transaction to meet the needs for emotional, instrumental, informational, and/or appraisal support (House, 1981).
 - a. Emotional support fosters feelings of comfort and security leading an individual to feel loved, respected, understood, and cared for. Emotional support means the availability of a person with whom one can discuss problems, share feelings, and disclose worries when necessary.
 - b. Instrumental support provides direct help or material aid.
 - c. Informational support provides information or guidance to help a person better understand and adjust to changes in his/her life;

- d. Appraisal support pertains to self-evaluation, acknowledging that one's beliefs and interpretations of a situation are appropriate.

Each of these types of support has also been classified into other typologies (Kahn & Antonucci, 1980; Norbeck, 1985). However, these four types of support constitute a minimal set of elements inclusive in other conceptions of the term.

Social support is operationally defined by the Nurse - Sibling Social Support Questionnaire (NSSSQ) developed by the principal investigator. The NSSSQ is a 30-item, Likert scale instrument. This self-report measure asks respondents to indicate the extent to which they believe each of 30 nursing interventions help them with the childhood cancer experience and how frequently the interventions are made available to them by pediatric nurses. Helpfulness ratings range from Not Helpful (1) to Extremely Helpful (5). Frequency ratings range from Never (1) to Always (5).

(2) Social support interventions are defined as actions implemented to provide supportive care to siblings of children with cancer.

(3) School-age siblings of children with cancer are defined as children related through birth (blood ties), step ties, adoption, or through sharing the same household. Siblings will range in age from 7 to 12 years.

(4) Parent is defined as a primary caretaker related through birth (blood ties), step ties, adoption, or through sharing the same household.

Significance of Study/Relevance to Nursing

The need to assess sibling perceptions of support and to relieve adjustment problems has been emphasized by clinicians and researchers (Murray, 1995; Carpenter & Levant, 1994). In 1996, the Association of Pediatric Oncology Nurses identified the urgency to address the needs of siblings of children with cancer as one of their top ten research priorities (Association of Pediatric Oncology Nurses, 1996). This study was also aimed at meeting Objective 6 of Healthy Children 2000 which is to reduce the prevalence of mental health disorders among children and adolescents (U.S. Department of Health and Human Services, 1991).

The identification of siblings' perceptions of helpful nursing interventions to provide social support to minimize the impact of childhood cancer on healthy siblings aids in the evaluation of current practices unique to the pediatric oncology work setting. This information will help nurses to evaluate whether their approach to the care of the pediatric cancer patient includes siblings in the process and provides interventions that are indeed helpful to sibling adaptation to the childhood cancer experience. This insight into pediatric oncology nursing practice has the potential to result in the adoption of new intervention strategies to

facilitate the healthy siblings' emotional adaptation to the childhood cancer experience.

Information about these nursing interventions would be instrumental in the academic setting as well. Faculty can use this knowledge to teach students in undergraduate and graduate programs the effects of the childhood cancer experience on healthy siblings. Students will learn that, just as with the child with cancer, a comprehensive approach to sibling intervention is necessary and requires the psychosocial assessment of non-disease as well as disease-related stressors. Ultimately, health care professionals' increased knowledge may result in a decrease in the incidence of adjustment difficulties and the enhancement of coping with an adaptive outcome.

Chapter II

Review of the Literature

The review of the literature is arranged into four sections: sibling relationships, siblings of disabled and chronically ill children, siblings of children with cancer, and social support. The impact that siblings have on each other has great significance. Changes in family characteristics as a result of working parents and single-parent families has made this relationship between siblings increasingly meaningful (Dunn, 1991). Difficulties in families, such as chronic illnesses or disabilities, create special challenges for siblings. For this reason, a brief review of the literature on sibling relationships is provided. In addition, a review of the related literature on siblings of disabled and chronically ill children is provided to demonstrate the impact of the illness experience across various childhood illnesses. Finally, a brief review of the literature on social support will be provided. When confronted with the childhood cancer experience, siblings have to learn to adapt psychosocially to a stressful situation. The support siblings receive from family, friends, and others during the illness experience is crucial in adjusting to changes occurring as a result of this experience. Social support has been demonstrated to influence health and promote adjustment to stressful life events. For this reason, a review of the social support literature will be presented.

Siblings

Sibling Relationships. Researchers have begun to recognize that siblings have a major impact on one another's behavior and development. Relationships between siblings serve as a model for later relationships with peers and adults (Dunn, Slomkowski, & Beardsall, 1994). Therefore, sibling relationships have been studied by child development researchers to learn how positive traits such as affiliativeness, altruism, and empathy, as well as negative traits such as self-centeredness and aggressiveness, emerge (Cicirelli, 1995). Much of what has been learned about sibling relationships comes from studying families in which none of the children has a chronic illness or disability (Breslau & Prabucki, 1987). From this research, investigators have learned about characteristic differences in how young siblings relate to older ones, how brothers relate to sisters, and how all children come to realize that they must learn to share and cooperate (Dunn & Plomin, 1991).

Siblings have an effect on one another's behavior, learning, and development throughout the life span (Dunn, 1991). This influence can be short- or long-term, direct or indirect, and can involve basic socialized learning as well as distinctive learning. For example, short-term influence of siblings takes place in the immediate present; long-term effects are found when one sibling learns certain characteristics, expectancies, or skills from another sibling that result in influences on future learning or behavior. Direct influence occurs when one

sibling interacts with the other to change some aspect of behavior, or one sibling communicates certain ideas, skills, expectations, or attitudes that might affect the immediate or future behavior of the other. Indirect influence occurs when a direct effect of a sibling interacts with some other variable to bring about a change later in time, or when one sibling influences another family member who in turn influences another sibling (Dunn & Plomin, 1991; Dunn et al., 1994). For example, an older sibling tells his parents that his younger brother is having trouble making friends in a new school. In turn, the parents speak with the younger brother and provide him with suggestions of ways to make new friends.

Experimental studies (Dunn, 1983; Dunn, 1991; Dunn & Plomin, 1990; Stocker, Dunn & Plomin, 1989; McHale & Gamble, 1989) that examine sibling relationships show that siblings display reciprocity in their relationships. This reciprocity - understanding the other and sharing his or her experiences - means that what distresses, pains, or excites one sibling, also distresses, pains, or excites the other sibling. Although factors such as gender, temperament, and parental treatment help explain some of this reciprocity, Dunn (1991) has found birth order and sibling spacing to be of greater importance. Siblings closer in age, and with less age difference, are more likely to display this reciprocity (Dunn, 1991).

When there is a chronically ill or disabled child in the family, the sibling relationship is oftentimes changed. The influences siblings have with each other change the usual rules about acceptable behavior and the amount of parental

attention each child receives changes (Frank, 1996). Parents tend to be preoccupied with the ill child and give their other children little attention (Spinetta, 1981; Trahd, 1986; Williams, Lorenzo, & Borja, 1993). The well siblings are often assigned extra chores or caregiving activities (Kramer, 1981). The relationship of the well sibling with the ill sibling is also affected. A number of factors related to the adjustment of siblings of children with chronic illness and disability have been reported in the literature. Adjustment can be affected by such factors as birth order, gender, family size, onset of illness, characteristics of the ill child, and characteristics of the parents (Williams et al., 1993).

Sibling Relationships and Chronic Illness. Research suggests that having a chronically ill or disabled brother or sister is more difficult for sisters. McHale and Gamble (1989) found that older sisters are more likely than older brothers, or younger siblings of either gender, to be engaged in caregiving tasks and are often expected to function as a surrogate caretaker. Sisters are also reported to experience more negative interactions with the mother and ill sibling (McHale & Gamble, 1989). Siblings who spend more time caring for their ill siblings, have less time to do other things such as participate in activities with peers (Murray, in press a). As a result of this, the well sibling tends to be resentful (Kramer, 1981; Spinetta, 1981).

The sibling's age influences his or her adjustment, with older children having better adjustment than younger children (Boer & Dunn, 1992; Breslau &

Prabucki, 1987). The effect of age is not surprising. Considering younger children's limited understanding of the ill child's condition; older children are more able to put the illness situation in some perspective. Researchers have also found birth order of the healthy sibling with respect to the ill sibling is important. Boyce and Barnett (1993) found that when the healthy sibling is younger, there may be problems associated with assuming greater responsibilities within the family system. Furthermore, the closer in age spacing the well sibling is to the ill sibling, the greater the adjustment difficulties. Siblings at wider age spacing have less interests and needs in common and there is less likelihood of competition and rivalry (Boyce & Barnett, 1993). A well sibling who is several years older will have experienced some years of "normal" family life before the ill child influences the family system. On the other hand, when the healthy sibling is several years younger, the care of the ill sibling is likely to already be taken over by other family members (Dyson, 1989).

Another factor found to influence adjustment is the number of children in the family. Research has found that well siblings adjust better as the size of the family increases (Lobato, 1990). If the well sibling has at least one other healthy sibling, adjustment to the illness experience is easier. The healthy siblings can share caregiving responsibilities and also provide support to one another.

In the case of chronic illness or disability with a later onset, the age of the well sibling at the time the condition is diagnosed may be an important factor.

Both the healthy and ill sibling will have had the opportunity to develop a relationship before the onset of the illness or disability; however, the well sibling may suffer the effects of loss of parental attention and problems of the family's adjustment to the chronic illness or disability (Lobato, 1990).

Characteristics of the ill child affecting the well sibling's adjustment include the ill child's competence level and the social acceptability of the child's appearance and behavior (Boyce & Barnett, 1993). In general, the higher the functional level of the ill or disabled child, the better the well sibling's adjustment. Furthermore, helplessness or behavior that is intrusive, socially objectionable, or embarrassing can be associated with adjustment difficulties (Boyce & Barnett, 1993; Lobato, 1990).

Finally, the parents' characteristics have been found to be important. Parents at a higher socioeconomic status can afford to hire additional help for the ill child, but may also place more achievement pressures on the well child (Lobato, 1990). Parents at lower socioeconomic levels tend to place more caretaking responsibilities on the healthy sibling (Lobato, 1990). Other research studies have reported the most important factors influencing the well sibling's adjustment to chronic illness or disability to be the attitudes, acceptance, and adjustment of the parents (Cohen, 1985; Dyson, 1989; Simeon, 1984; Simeonsson, 1981).

In summary, when one sibling has a chronic illness or disability, sibling activities that can be shared with a healthy sibling can be circumscribed, depending on the severity of the illness or disability. The extent of the effects of the chronic illness or disability depends to a large extent on the family structure and dynamics. In many families, the responsibility of well siblings for the care of the chronically ill or disabled child, extends throughout the well siblings' childhood and in many cases their life span. It is clear that unusual demands are placed upon the sibling relationship in such instances.

Siblings of Disabled and Chronically Ill Children. Research on siblings of children with developmental disabilities or other chronic medical illnesses suggests they can be at risk for adjustment problems as is the case in childhood cancer. Although the literature relating to the incidence of psychosocial problems among siblings of disabled and/or chronically ill children is somewhat contradictory, some similarities with siblings of children with cancer have been noted.

Lavigne and Ryan (1979) compared the psychosocial adjustment of siblings of pediatric cardiology patients, pediatric plastic surgery patients, pediatric hematology patients, and healthy children. The findings of this study suggest that siblings in all three groups were more likely to experience adjustment or behavior problems than the siblings of healthy children. Problems experienced included social withdrawal, irritability, and fear. In another study, Tew and

Laurence (1973) investigated the social adjustment of siblings of children with spina bifida and found very interesting results. Not only were siblings four times more likely to show evidence of maladjustment than siblings of control children, but siblings of slightly disabled children were more disturbed than siblings of severely disabled children. In 1980, Taylor conducted a study designed to elicit descriptions of the effects of long-term childhood illness directly from well siblings. Twenty-five healthy, school-aged siblings of children with asthma, congenital heart disease, or cystic fibrosis participated in the study. Findings reported by the researcher included sibling feelings of jealousy, isolation, social withdrawal, and loss of parental time and attention.

A preponderance of other studies reviewed also reported an increased risk in well siblings which were evident in various ways. These manifestations included higher internalizing and externalizing behavior problems and lower social competence on the Achenbach and Edelbrock's Child Behavior Checklist (Engstrom, 1992); low self-esteem (Engstrom, 1992; Ferrari, 1987; Harvey & Greenway, 1984); withdrawal or shyness (Tritt & Esses, 1988); somatic complaints (Cowen et al., 1986); poor peer relations or delinquency (Breslau & Prabucki, 1987; Cadman, Boyle, & Offord, 1988, Engstrom, 1992); feelings of loneliness, isolation, anxiety, depression, vulnerability, anger, worry about the ill child (Breslau & Prabucki, 1987; Engstrom, 1992; Menke, 1987); and school performance difficulties (Vance, Fazan, Satterwhite, & Pless, 1980). A decrease

in school grades was reported in another research study (Williams et al., 1993).

The change in grades was related to time since diagnosis.

Despite the fact that evidence exists in the literature to support the reality that siblings of children with disabilities or chronic illness experience difficulties adjusting, such problems are by no means universal. Many siblings of disabled or chronically ill children do not develop problems and appear to function effectively under stress. Several studies throughout the literature have reported positive effects on siblings of disabled or chronically ill children. Studies by Siemon (1984), McKeever (1983) and Simeonsson (1981) identified that while being a sibling of a disabled or ill child can create vulnerabilities, it can also engender strength, sensitivity, compassion, and empathy. In addition, although Taylor (1980) noted the negative impact of disability or illness on siblings, she also noted that there are benefits that accrue to the siblings. For example, she noted increased levels of maturity and responsibility, sensitivity, and compassion.

In summary, siblings of children with disabilities and chronic illnesses are at increased risk for adjustment difficulties. Although extensive research has been done in the area of chronic illness and sibling response, many problem areas have been noted and have contributed to research efforts that are conflicting. Studies of siblings of children with chronic illnesses should focus on interventions in clinical practice to reduce the incidence of adjustment difficulties. In addition, more

knowledge is needed about what specific variables predispose a sibling to long-term difficulties with adjustment and how these change over time.

Siblings of Children with Cancer

The review of the literature on siblings of children with cancer is organized into eleven domains according to study variables. The first domain includes early studies examining sibling response to illness. The second domain contains a review of the effects of childhood cancer on healthy siblings during the illness experience. Positive effects of the cancer experience on healthy siblings are discussed in domain three. The fourth domain encompasses the minimal effects of the cancer experience on healthy siblings. Domain five includes predictors of sibling adjustment followed by sibling coping strategies in domain six. Sibling facilitative behaviors are examined in domain seven. Domain eight consists of nursing interventions to provide social support to healthy siblings. The lived experience of a healthy sibling is investigated in domain nine. Barriers to supporting siblings during the childhood cancer experience are discussed in domain ten. The final section provides a synthesis of research findings and directions for future research.

Early Studies Examining Sibling Response to Illness. The first studies reviewed are three classic retrospective studies. They reported evidence that siblings of a child who dies are at increased risk for developing severe psychosocial problems. The earliest research in this area, conducted by Cobb

(1956), was initiated to look at the psychological impact of illness and death on the family. A major focus was the impact of cancer on other children in the family. A convenience sample consisted of parents of children who died of cancer. The author used a retrospective exploratory design with an unstructured interview guide. Major findings reported by parents, included feelings of loneliness, sadness, and loss of parental availability to siblings. Concluding statements reflected the need to consider the psychological impact of the disease and death of the child on the entire family (Cobb, 1956).

In 1964, Cain, Fast, and Erickson studied children's disturbed reactions to the death of a sibling. This retrospective exploratory study was undertaken in an attempt to investigate the range of enduring symptoms and character changes resulting from sibling death reactions. The convenience sample consisted of 58 children between the ages of 2-1/2 to 14 years who were psychiatric patients being seen in both inpatient and outpatient mental health facilities. Their presenting symptoms in therapy were noted to be related to the death of their sibling. Most of the data was collected from files of materials ranging from outpatient evaluations to years of inpatient treatment. Standardized unstructured interviews were employed with clinical observations. The authors found that the most immediate reactions had a heavy emphasis on guilt, which remained consciously active five years or more after the sibling's death. Reactions to the guilt included depression, withdrawal, becoming accident prone, and constant

acting out behaviors. Ultimately, these behaviors led to poor school performance and feelings of low self-worth. Another major recurring theme was that of distorted concepts of illness and death. Present in all the children's responses was a heightened fear of death and fear of contracting the same illness that caused their sibling's death. The authors concluded that further clinical study of the psychopathology of siblings of children who have died would be of immense preventive value (Cain, Fast, & Erickson, 1964).

Binger et al. (1969) reported that, in approximately half of 20 families studied, one or more of the previously well siblings showed significant maladaptive behavioral patterns during the patient's illness that were indicative of coping difficulties. These problems intensified following the death of the ill sibling. A child psychiatrist interviewed the parents of these families, who were conveniently sampled, regarding the impact of the crisis and its consequences upon their lives. The unstructured interview was two to three hours in length and elicited information including the following: details surrounding the diagnosis; short and long-term effects upon patient, parents, siblings and family unit; sources of support and the after effects of the illness following the ill child's death. The findings showed that siblings experienced the onset of severe enuresis, headaches, poor school performance, severe separation anxiety, and feelings of rejection, fear, and guilt. The authors concluded that supportive therapy for siblings should be considered an essential aspect of total care of the family (Binger et al., 1969).

These early studies are important because they extended the focus of attention to siblings. However, because of the small sample size, weak research designs, use of psychiatric cases, and major emphasis on after death responses, they have a limited scope of application. Based on these findings and concerns, researchers began to examine problems in the sibling during illness.

Effects of Childhood Cancer on Healthy Siblings During Illness. Cairns, Clark, Smith, and Lansky (1979) were the first researchers to take this new approach of focusing on healthy siblings during the illness experience. Utilizing an exploratory design, they looked at the impact of childhood cancer both on the patients and their healthy siblings in 71 families. Subjects were conveniently selected at a large medical center. Instruments used included the Piers-Harris Children's Self Concept Scale to assess the children's perception of themselves, the Bene-Anthony Family Relations Test to assess perceived family roles, and the Thematic Apperception Test (TAT). Scores from the Piers-Harris and Family Relations Test were analyzed using t-test for separate samples and chi-square tests to investigate the possibility of sex differences among the patient or sibling groups. A t-test for matched pairs was computed on available data from patient-sibling pairs. TAT scores were analyzed using analysis of variance. A discriminant analysis was also completed to determine whether the subjects could be identified accurately as patients or siblings on the basis of one or more variables in their TAT productions (Cairns et al., 1979). Enough differences were

present to enable the researchers to identify respondents. Specific statistical values were not reported (Cairns et al., 1979).

Results of the study revealed siblings of children with cancer have significant anxiety and periods of depression. Siblings also feel very isolated from parents, extended family members, and friends. On the Family Relations Test, sex differences were noted with respect to feelings. The boys in the patient group and the girls in the sibling group did not feel that good feelings by other family members were directed toward them. Recommendations were made to address the needs of the well siblings and to implement specific measures (i.e., encouraging visitations and support groups) to facilitate a healthy adaptation to the situation (Cairns et al., 1979).

Spinetta (1981) conducted a three-year longitudinal study of families with a child diagnosed with cancer, which included 102 siblings. The primary focus of this research was to study siblings in the context of, and in relation to, the family system. The subjects for the study were the siblings of children with cancer ranging in age from 4 to 18 years. Informed consent was obtained from the parents and the siblings in the study. Instruments used to collect data included the Brown IDS Self-Concept Reference Test, Family Relations Test, Roberts Apperception Test, and the Family Environment Scale. The statistical analysis used was not discussed in the report. The results showed that siblings' emotional needs were met at a significantly lower level than those of other family members.

The author also found several age-related differences on the dependent variables between the siblings and the ill child. Siblings between the ages of 4 and 6 had significantly lower self-concept scores and a more negative attitude toward self than the patients did. They also viewed parents as psychologically more distant. Siblings between the ages of 6 and 12 years had more maladaptive levels of anxiety, depression, and maladaptive responses (e.g., acting out behaviors). The investigators strongly suggested that sibling adjustment needed to be addressed by professional caregivers. Recommendations were made to conduct further studies to examine age-related differences to sibling adaptation (Spinetta, 1981).

Research conducted to this point identified several negative effects of the cancer experience on healthy siblings. However, pediatric oncology nurses working with families of children with cancer began to observe that the effects of the illness experience were not all troublesome.

Positive Effects of the Cancer Experience on Healthy Siblings. Although research has identified many negative effects of the cancer experience on healthy siblings, researchers have identified some positive effects as well. The following studies have found both positive and negative effects of having a sibling with cancer. Kramer (1981) was the first nurse to study siblings of children with cancer and the first researcher to explore the possible benefits of having a sibling with cancer. This exploratory qualitative study was undertaken to identify the special needs of siblings from their perspective. Eleven siblings of children with cancer

made up the sample of convenience. Ages ranged from 7 to 11 years. Data were obtained from a taped open-ended interview. Content analysis of the data revealed both negative and positive consequences of sibling illness. Negative consequences included emotional stress, sense of emotional deprivation, decrease in parental tolerance, increase in parental expectations, anger, and guilt. Positive consequences identified were an increased sensitivity and empathy for the patient and others, enhanced personal maturation, and an increased appreciation for life. Further analysis of the data identified three critical factors in facilitating adaptive outcomes. Siblings wanted information about the disease, treatment, and patient's condition. Open and honest communication was given primary importance. Finally, all siblings expressed a desire to be actively involved in the sick child's care. The author made recommendations as to how to meet these needs: encourage open communication, express feelings, provide information about the disease, and encourage participation in the ill child's care (Kramer, 1981). These interventions are aimed at providing emotional, informational, and instrumental support as described by House (1981).

In a pilot study, Iles (1979) examined the experiences of five healthy siblings of children with cancer during the illness experience. This study was undertaken to determine the feasibility of conducting a longitudinal study examining the same topic. The sample was conveniently selected at a major Southwestern medical center. Subjects ranged in age from 7 to 12 years and their

siblings were each in a different stage of the childhood cancer experience. Data were obtained through a taped, 45 to 60-minute, semi-structured interview. Open-ended questions facilitated discussion of each subject's perceptions regarding family life, the ill sibling, and the child during current experiences. Subjects were also asked to draw pictures of their families. Taped data were transcribed for analysis and the researcher and a nurse-social worker from a pediatric oncology setting tabulated perceptions. Negative consequences included feelings of loss of quantity and quality of time with parents, changes in family routines, and altered peer relationships. Positive consequences noted were increased empathy for parents, respect for the ill child, and improved self-concept. Recommendations were made for future research using a longitudinal design (Iles, 1979).

Havermans and Eiser (1994) interviewed 21 well siblings about their experience when a brother or sister is diagnosed with cancer. Information about the illness, perceptions regarding who should inform siblings, social support, specific concerns, and worst memories were investigated, as well as perceptions of any differences in the way they were cared for by parents. A short General Impact Scale was developed to assess the extent to which the well siblings felt their lives had been interrupted by the cancer experience. Results on these measures were compared with scores on four dimensions of the Sibling Perception Questionnaire. Siblings who reported some positive effects as a consequence of the illness experience (they had become more empathetic toward

others, or valued life more) perceived their interpersonal relations to be more negatively affected (i.e., there were greater difficulties in their relationships with others, especially their parents). Higher scores on communication were related to less of an impact of the illness experience on life in general. However, these well siblings also reported heightened concerns that their brother or sister might die. The researchers suggested that siblings should have opportunities to talk about implications of the disease, especially worries about death, and more efforts should be made to prepare siblings for visits to the hospital setting and seeing the child with cancer (Havermans & Eiser, 1994). Each of these opportunities provides the healthy sibling with emotional support (House, 1981; Murray, 1998).

In summary, these studies demonstrated that there are some positive outcomes from having this experience. Additional research has been conducted that identifies that some siblings adjust to the stressors of the childhood cancer experience with minimal disruption.

Minimal Effects of the Cancer Experience on Healthy Siblings. The results of the following studies demonstrate that the effects of childhood cancer experience on well siblings may be minimal. A study conducted by Koch-Hattem (1986) was designed to increase available information about siblings' perceptions of changes in their selves, as well as their families, which occur after the diagnosis of pediatric cancer. An exploratory quantitative and qualitative approach was utilized. Interviews were conducted in the homes of subjects. The

interview schedule contained 30 forced-choice questions related to changes the siblings experienced after the diagnosis was made. In addition, open-ended questions were asked exploring how they coped with these changes. Interviews averaged 50 minutes in length (Koch-Hattem, 1986).

A single-sample chi-square was used to test for differences among the response choices. The analysis yielded two notable findings. More siblings reported no change in their experiences following the diagnosis than reported either negative or positive changes. The second finding showed a negative change in affect. Siblings described feeling bothered, sad, and scared more often after the diagnosis of the illness than before. The results of the study showed that siblings' perceptions of the cancer experience are organized around affect (Koch-Hattem, 1986). Suggestions for future research were similar to those of Iles (1979).

A study conducted by Van Dongen-Melman, De Groot, Hahlen, and Verhulst (1995) investigated the aftereffects of the childhood cancer experience on well siblings. The sample of 60 siblings of cancer survivors was compared with control subjects on measures of psychosocial adjustment. The researchers found no differences between siblings of children that survived childhood cancer and controls on emotional and behavioral problems and competence. These findings suggest that siblings adjust well to the period after the treatment has ended. The effect of demographic, family, and disease-related characteristics on the siblings' psychosocial adjustment was limited. During the ill child's treatment

for cancer, many psychosocial problems for siblings have been reported. However, this may not result in a heightened risk of psychological disturbance for siblings as a later effect (Van Dongen-Melman et al., 1995).

Zeltzer et al. (1996) conducted a multi-site study to examine the overall health status, utilization of healthcare services, physical complaints, and health-risk behaviors of well siblings of children with cancer compared to these factors in matched controls or normative data. Furthermore, the study also considered whether well siblings, parents, and physicians differed in their assessments of the earlier mentioned health domains. The sample was comprised of 254 healthy siblings of children with cancer from seven different pediatric oncology treatment centers. Each of these centers participated in the Sibling Adaptation to Childhood Cancer Collaborative study group. Predictors of the siblings' health status, utilization of healthcare services, physical complaints, and health-risk behaviors were identified, and the relationship between these health domains and the siblings' resiliency versus dysfunctionality were explored by individual interviews. The researchers reported that siblings were found to be moderately healthy, although they did report problems with sleeping and eating. In addition, utilization of health care services appears to be diminished for siblings. Parents of these siblings are also less likely to seek health care services for a variety of ailments for which parents of control children would bring their children to the doctor. The researchers noted that "a pattern emerged of parental underreporting

of sibling health variables when compared to what the sibling themselves reported" (p.103). When the relationship between health outcomes and the well siblings' adaptation to their sick sibling's illness was evaluated, the resilient and dysfunctional groups were significantly different from each other. Based on these findings, the researchers determined that health outcomes are related to sibling adaptation to the changes brought about by their ill brother or sister's cancer experience. The well siblings may be left out during the cancer experience in terms of recognition of their physical symptoms by their parents and in terms of receiving health care. While parents appear to recognize that their healthy children are complaining more about physical symptoms such as aches and pains, they may have limited resources (i.e., financial and/or emotional) to attend to the needs of other family members. For example, the financial burden placed on the family by the illness might limit financial resources for other needs. The authors concluded that the focus of care for families of children with cancer is often limited to the child with the pediatric malignancy. As indicated in this study, the "healthy" siblings may be overlooked in the process of treating the child with cancer (Zeltzer et al. , 1996).

The fact that these studies did not demonstrate an increased risk of major adjustment problems does not signify that siblings do not experience distresses or undergo changes in psychosocial functioning. Studies on variables found to

predict sibling adjustment to the childhood cancer experience have also been conducted.

Predictors of Sibling Adjustment. Cohen (1985) conducted a study to investigate the adaptation of well siblings to pediatric cancer and of the variables that may be related to that adjustment. A sample of 129 families of pediatric cancer patients participated in the study. Parents were given a series of mailed questionnaires developed to assess coping, details of the illness, the level of parent-child communication, and the adjustment of the sibling closest in age to the ill child. Siblings were administered a Brother/Sister Questionnaire and the Child Behavior Checklist for ages 4 to 16 years. The researcher found that siblings displayed significant adjustment problems when compared to the norms of the Child Behavior Checklist. Significant predictors of sibling adjustment were also identified in the study. These included: parent depression, marital adjustment, annual family income, neighborhood/community social support, parent-sibling communication about the illness, and time since diagnosis (Cohen, 1985). Neighborhood and community social support meets the sibling's need for instrumental support; parent-sibling communication about the illness meets the need for informational support (House, 1981).

Cohen (1985) recommended that other studies be conducted to investigate variables that may be related to coping. In addition, it was suggested that

longitudinal studies be designed to determine if adjustment difficulties are healthy and a necessary part of the coping process.

In 1996, Wang and Martinson explored the adjustment of healthy Chinese siblings living in Taiwan to the childhood cancer experience. The researchers investigated factors that contributed to the presence or absence of behavioral problems in siblings. The sample consisted of 45 Chinese families. These families were selected through referrals and a cancer foundation name roster. Instruments used included the Piers-Harris Self-Concept Scale, Child Behavior Checklist, and Family Environment Scale. Analysis of sibling data revealed significant stressor themes of inadequate knowledge, reduced family communication, and insufficient support. Healthy Chinese siblings showed significantly more behavior problems (i.e., acting out, school disruption) and fewer social competence behaviors than a standardized normal western population. Recommendations made by the researchers discussed the need for nurses in clinical practice to complete comprehensive assessments of well siblings in every family who has a child with a diagnosis of cancer. Furthermore, recommendations were made for prospective research examining well siblings' behavioral responses to the childhood cancer experience compared with a control group of siblings of healthy children or well siblings of children with a disease process other than cancer. The purpose of this research would be to ascertain whether the responses of well siblings of children with cancer are unique to this sibling population (Wang & Martinson, 1996).

Another study in 1996 conducted by Sloper and While, investigated the psychological adjustment of 99 siblings of children with cancer. The subjects ranged in age from 8 to 16 years. Six months after diagnosis, 24 siblings had scores in the borderline or clinical range on parent and teacher completed measures of behavioral adjustment. These siblings were also reported to have shown negative changes in behavior since diagnosis. Data were analyzed using logistic regression analysis. Adjustment difficulties were related to the degree of disruption of family life occasioned by the illness, the resources available to the family to cope with the effects of such disruption on siblings, and siblings' perceptions of negative interpersonal effects on their lives (Sloper & While, 1996).

The need to identify factors that will help predict sibling adjustment to the childhood cancer experience, as well as identify those variables that place siblings at increased risk, is great. The paucity of research in this area indicates the need to examine additional variables that may predict sibling adjustment difficulties and enable health care professionals to identify strategies to enhance coping.

Sibling Coping Strategies. In an effort to identify and describe coping strategies used by well siblings to contend with the stressors imposed as a result of the childhood cancer experience, the following studies were conducted. Walker (1988) conducted a qualitative study to identify and describe behavioral and cognitive coping strategies used by siblings. Twenty-six siblings of pediatric

oncology patients aged 7 to 11 and their parents were studied. This sample of convenience was selected from families of pediatric oncology patients being treated at a regional children's hospital. Open-ended interviews with the parents were designed to identify stressors on the family and the effects of these stressors on the sibling(s). The same type of interview with the sibling focused on what the child saw as stressors and what thoughts and behaviors were used to deal with the stressors. Puppet play, family drawings, cartoon story telling, and sentence completion tests were used to facilitate communication regarding coping efforts. Content analysis was used to analyze data. The results demonstrated that parents reported physiologic (e.g., weight change and somatic complaints), social (e.g., less desire to play), and affective responses (e.g., acting out and emotional lability) in the siblings. Sibling data reveal three major themes of stressors: loss, fear of death, and change. Coping strategies used by siblings included wishful thinking, talking to others, attention seeking behaviors, and solitary play. Recommendations by the investigator included replication of this research study with a larger and more diverse population (Walker, 1988).

Heffernan and Zanelli (1997) investigated the coping strategies used by well siblings of children with cancer as identified by both the primary caretaker and the well siblings. A nonprobability purposive sample of 17 mothers was selected from a computerized census list. Following selection, the mothers completed the modified Parental Assessment of Sibling Coping Strategies

(PASCS). Twenty-one school-age and adolescent siblings ranging in age from 9 to 18 years completed the modified Sibling Coping Ability Assessment (SCAA). Similarities and differences between maternal and sibling descriptions were evident in the investigation. The findings showed that both mothers and the well siblings were able to identify behavioral changes (95.2% of the mothers and 85.7% of the well siblings identified behavior changes). Behavior changes identified by both the siblings and mothers included being more sensitive to the needs of others, being more thoughtful, playing with friends, fighting, trouble sleeping, and complaints of somatic symptoms such as headaches. The authors recommended that nurses conduct thorough assessments of sibling behavior changes when a child family member has been diagnosed with cancer. From these assessments, nurses can provide care to assist the entire family during the ill child's treatment (Heffernan & Zanelli, 1997).

Research findings from previous studies indicate that siblings of pediatric oncology patients exhibit stress responses to the illness experience. These research findings demonstrate that coping strategies used by well siblings could provide nurses with information to use in the successful coping of well siblings.

Nursing Interventions to Facilitate Coping Behaviors. Previous research has identified coping strategies used by children with cancer and more recently siblings of children with cancer. The following study was conducted to determine what nurse's perceived to be helpful in family members' adaptation to the

childhood cancer experience. Walker et al. (1992) conducted a Delphi study to identify and describe nursing behaviors that facilitate the coping efforts of children with cancer and their families. More specifically, the study was conducted to identify what nursing behaviors or interventions nurses believe to be most important in facilitating the patients', parents', and siblings' coping efforts with the effects of the disease of childhood cancer and its treatment. The subjects were a random selection of 300 pediatric oncology nurses from the Association of Pediatric Oncology Nurses (APON). Only nurses completing all three rounds of the study were included in the final sample of 69. The Delphi survey technique involved three rounds of data collection with successive rounds building and refining results from the previous rounds (Walker et al., 1992).

In the data analysis, all facilitative nursing behaviors identified following round one were listed and reviewed by a collaborative research team. Data obtained from rounds two and three were analyzed using descriptive statistics. From round three data, group means for each nursing behavior were reported. Results demonstrated that open communication was rated as one of the most important facilitative behaviors for patients', parents', and siblings' groups. Other common sibling facilitative behaviors included making siblings feel special, encouraging consistent discipline for all children, and encouraging visits to the hospital/clinic (Walker et al., 1992). These nursing behaviors to promote sibling adaptation to the illness experience meet the well sibling's needs for emotional

and instrumental support (House, 1981). The authors suggested that the patients, parents, and siblings be asked what they believe nurses should do to facilitate their coping with the childhood cancer experience.

The previous study provided insight into what nurses believed to be important interventions to provide for siblings of children with cancer. Although they believed these interventions were important in facilitating coping, the study did not address whether nurses actually implemented these interventions in clinical practice.

Nursing Interventions to Provide Social Support to Healthy Siblings.

Based on the previous study by Walker et al. (1992), the principal investigator for the next study was interested in knowing what interventions pediatric oncology nurses actually applied in clinical practice for siblings. In 1995, Murray conducted a descriptive study investigating nursing interventions used by pediatric oncology nurses to provide social support to siblings of children with cancer. Based on the social support research literature, the study was guided by House's (1981) conceptualization of social support which includes components of emotional, instrumental, informational, and appraisal support. A sample of 250 randomly selected pediatric oncology nurses were mailed the Sibling Social Support Questionnaire (SSSQ), developed by the researcher, to determine what interventions they use in clinical practice to provide social support to siblings of children with cancer. With 134 nurse respondents, the SSSQ demonstrated high

internal consistency (Cronbach's alpha of .95). Results indicated that the two most frequently used nursing interventions to provide social support to well siblings were: (a) encouraging parents to spend time with their healthy children, and (b) providing honest responses to questions asked by siblings. Recommendations were made to conduct future research that investigated sibling perceptions of helpful interventions aimed at enhancing sibling adaptation to the childhood cancer experience (Murray, 1995).

The researcher recommended that effective interventions with siblings of children with cancer should be included in a comprehensive approach to care. Furthermore, future studies should be conducted to determine what siblings perceive as helpful interventions in coping with the stressors of the childhood cancer experience (Murray, 1995).

The Lived Experience With Childhood Cancer. In trying to obtain an understanding of a sibling's experience with the childhood cancer experience, the following research endeavor was undertaken. In 1998, a phenomenological study with a sibling of a child with cancer was conducted (Murray, 1998). The purpose of this study was to gain a better understanding of the lived experience of one 14-year-old sister's experience with childhood cancer. Through the qualitative research process of phenomenology, the researcher gained a greater understanding of the participant's experience and how the childhood cancer experience affected her and her family. Themes that emerged through the process of content analysis

included: emotional intensity, increased empathy for others, personal growth, need for support, and desire to help others. The researcher reported that this method of studying the effects of childhood cancer on siblings could be instrumental in formulating a supportive care approach to this population. Studying the meaning of the childhood cancer experience for siblings is in its infancy, with this study as one of the starting points in the research process. Future research should focus on conducting qualitative research with other siblings of children with cancer. In addition, purposeful sampling of siblings of children with other forms of cancer as well as participants from ethnically and culturally diverse backgrounds would be helpful and allow for the transferability of findings across cultures and disease processes (Murray, 1998).

The use of qualitative research in this study demonstrated that the sibling's lived experience with childhood cancer experience provided an insight that is unattainable by evaluating the parent's and health care professional's perception of the experience. This approach to research provides a meaningful measure that will assist health care professionals in assessing the impact of cancer on the well sibling.

Barriers to Supporting Siblings. Previous research has identified that pediatric oncology nurses report barriers to providing support to siblings (Murray, 1993). Murray (1999b) analyzed secondary data from a previous study which investigated nursing interventions used by pediatric oncology nurses to provide

social support to siblings of children with cancer (Murray, 1995). Results demonstrated that pediatric oncology nurses frequently reported staffing shortages, lack of access to siblings, institutional constraints, role boundary issues, and lack of support for sibling support groups as common barriers to meeting the needs of siblings. The findings of this investigation suggest that additional research is needed to determine the best way to provide interventions for siblings given the barriers reported (Murray, 1999b).

Refer to Table 1 for a summary of the siblings of children with cancer literature reviewed.

TABLE 1. Chronological Listing of Siblings of Children With Cancer Research Findings

Author	Design	Sample Size	Findings
Cobb (1956)	Retrospective Exploratory	Not stated	Feelings of loneliness, sadness Loss of parental availability
Cain, et al (1964)	Retrospective Exploratory	58	Feelings of guilt Poor school performance Low self-worth Distorted concepts of illness and death
Binger, et al (1969)	Retrospective	20*	Severe enuresis Headaches Poor school performance Separation anxiety Feelings of rejection, fear, guilt
Cairns, et al (1979)	Exploratory	71*	Anxiety Depression Social isolation
Iles (1979)	Pilot Qualitative	5	<u>Negative Consequences</u> Loss of parental time Changes in family routines Altered peer relationships <u>Positive Consequences</u> Increased empathy for parents Respect for ill child Improved self concept

TABLE 1. (Continued)

Author	Design	Sample Size	Findings
Spinetta (1981)	Longitudinal Exploratory	102	<p>Overall adjustment lower than patient's Parents viewed as psychologically distant</p> <p><u>Four-six year olds</u> Lower self-concept Negative attitude toward self</p> <p><u>Six-twelve year olds</u> Anxiety Depression Acting out behaviors</p>
Kramer (1981)	Exploratory Qualitative	11	<p><u>Negative Consequences</u> Emotional stress Sense of emotional deprivation Decrease in parental tolerance Increase in parental expectations Anger, Guilt</p> <p><u>Positive Consequences</u> Increased sensitivity and empathy for patient and others Enhanced personal maturation Increased appreciation for life</p>
Cohen (1985)	Exploratory	129*	<p><u>Sibling Adjustment Predictors</u> Parent depression Marital adjustment Family income Availability of support Parent-Sibling communication</p>

TABLE 1. (Continued)

Author	Design	Sample Size	Findings
Koch-Hattem (1986)	Exploratory Quantitative & Qualitative	32	No change in experience after diagnosis Feeling bothered, sad and scared Coped with feelings by using emotional expression
Walker (1988)	Qualitative	26	<u>Parent Reports</u> Physiologic, social and affective responses of siblings <u>Sibling Responses</u> Loss Fear of death Change <u>Sibling Coping Strategies</u> Wishful thinking Talking to others Attention seeking behaviors Solitary play
Walker, et al (1992)	Delphi	69 Nurses	<u>Sibling Facilitative Behaviors</u> Open communication Consistent discipline Visitation to hospital/clinic
Williams (1992)	Descriptive	17*	<u>Parent Defined Support</u> Affective support Instrumental support

TABLE 1. (Continued)

Author	Design	Sample Size	Findings
Havermans & Eiser (1994)	Descriptive Exploratory	21	<u>Positive Consequences</u> More empathetic Greater value of life <u>Negative Consequences</u> Difficulties in relationships Heightened concerns over ill sibling
Murray (1995)	Descriptive	134 Nurses	<u>Interventions Providing Support</u> Encourage parental time with siblings Provide honest responses to questions asked by siblings
Van Dongen - Melman, et al (1995)	Descriptive	60	No differences found between siblings of cancer survivors and controls on emotional and behavioral problems and competence
Wang & Martinson (1996)	Longitudinal Exploratory	45*	<u>Major Stressor Themes</u> Inadequate knowledge Reduced family communication Insufficient support
Sloper & While (1996)	Descriptive	24	Adjustment problems were related to degree of disruption of family life, lack of resources

TABLE 1. (Continued)

Author	Design	Sample Size	Findings
Zeltzer, et al (1996)	Exploratory Multi-Site	254	Siblings were found to be moderately healthy although they reported problems with sleeping and eating
Heffernan & Zanelli (1997)	Descriptive	21	<u>Sibling Behavior Changes Identified</u> More sensitive to needs of others More thoughtful Difficulty sleeping Somatic complaints
Murray (1998)	Qualitative Phenomenological	1	<u>Emerging Themes:</u> Emotional intensity Increased empathy for others Personal growth Need for support Desire to help others
Murray (1999)	Methodological Triangulation	25 Nurses	<u>Barriers to Supporting Siblings</u> Staffing Issues Access to Siblings Institutional Constraints Role Boundaries

*Indicates the number of families in the study.

Summary of Siblings of Children With Cancer Research Findings. The

previously cited review of the literature on siblings of children with cancer clearly shows that the childhood cancer experience is a stressor that may increase subjective feelings of stress by well siblings and in some cases lead to decreased psychosocial competencies and increased psychopathologies. Murray (1995) and Walker (1990) cite that research on siblings with cancer has made some progress over the past few years. Research has expanded from identifying psychosocial problems after the patient's death to identifying stressors during the illness experience. These early studies are important because they extend the focus of attention to siblings. However, because of modest sample sizes, limited sampling techniques, and methodological issues (e.g. focus on post-death responses) these studies have limited use (Murray, 1999a).

Based on these findings and concerns, researchers in the late 1970's examined problems with the well sibling during the illness experience. Although research had previously identified many negative effects of the cancer experience on healthy siblings, researchers during the 1980's began to identify positive effects as well. Further research in this area in the latter part of the 1980's yielded contrasting notable findings. In an extensive literature review, (Murray 1999a) siblings reported no change in their experiences following the diagnosis than reported either negative or positive changes (Koch-Hattem, 1986).

The late 1980s and early 1990s provided research studies that investigated the adjustment of siblings to pediatric cancer and the variables that may be related to that adjustment, as well as research conducted to identify and describe behavioral and cognitive coping strategies used by siblings. More recent studies have been targeted at identifying what nursing behaviors or interventions nurses believe to be most important in facilitating the patients', parents', and siblings' coping efforts with the effects of the disease of childhood cancer and its treatment. In addition, descriptive research investigating nursing interventions used by pediatric oncology nurses to provide social support to siblings of children with cancer has been conducted (Murray, 1995). The concept of social support has been studied and described by a number of researchers. However, the most inclusive framework reported in the literature, including components of emotional, informational, instrumental and appraisal support, is that described by House (1981).

Social Support

The role of social support on the impact of illness has been widely researched. Social support has been considered to be a positive influence on health and well-being (Aaronson, 1989; Abbey & Andrews, 1985; Barrera 1981; Callaghan & Morrissey, 1993; Cohen & Wills, 1985; Friedman & King, 1994; Friedman, 1993; Keeling, Price, Jones, & Harding, 1996; Logsdon, McBride, & Birkimer, 1994; Procidano & Heller, 1983; Smith, Fernengel, Holcroft, Gerald, &

Marien, 1994; Wethington & Kessler, 1986; Yates, 1995). Social support also enhances psychological well-being (Fink, 1995; Friedman & King, 1994; Wheaton, 1985). According to Callaghan and Morrissey (1993) social support affects health in three ways: (a) by regulating thoughts, feelings and behavior so as to promote health; (b) by fostering an individual's sense of meaning in life; and (c) by facilitating health promoting behaviors. Based on the empirical research of Nelson (1990), social support is hypothesized to have a health-enhancing effect on positive affect and a health protecting effect on negative affect. Dunkel-Schetter and Bennett (1990) suggested that lack of social support reflected negatively on subjective well-being. Sauer and Coward (1985) advocate the effect of social support on well-being, however, they recommended the causal connections between these phenomena should be further examined.

The preponderance of existing research on social support has been used primarily in the adult population in a variety of clinical settings. When used in the pediatric population, the measurement tools are frequently used to measure social support for parents of children (Murray, in press a).

In 1992, a study by Tomlinson and Mitchell explored the nature of family social support during an acute-life threatening health crisis of a child. A convenience sample of 10 families was obtained from two pediatric intensive care units (PICUs) in a major Midwestern metropolitan area. Tape-recorded interviews of parents took place in the hospital 2 to 13 days after admission to the PICU. The

Family Crisis Support Interview (FCSI) was developed from existing literature on social support with content selected for specificity to this population. Qualitative analysis was used to reduce verbatim interview transcription data into four major categories with related themes. Results suggest that for these families (a) cost of support received sometimes outweighed the perceived benefits; (b) the benefit of the social network to parents was influenced by its density and level of connectedness; (c) mothers received more network support than fathers; and (d) dyadic cohesion was a central factor in perceptions of overall support (Tomlinson & Mitchell, 1992).

Speechley and Noh (1992) assessed whether the continuing emotional strain of parenting a child that survived having cancer is associated with elevated levels of psychological distress (depression and anxiety) in parents. The role of social support in moderating this relationship was also evaluated by the researchers. When parents of cancer survivors with healthy children were evaluated there were no differences in levels of depression or anxiety overall. Among those parents encountering low levels of social support, parents of cancer survivors were more depressed and anxious than parents of healthy children. According to the researchers, perceived social support had a significant inverse relationship with psychological distress for both parents but seemed to be more important for mothers (Speechley & Noh, 1992).

In another nursing study, Williams (1992) conducted a pilot study to describe how parents of children with cancer perceive support and the types of interventions they found supportive during their child's hospitalization. In addition, the parents' perceptions were compared with those of the health care professionals involved in the care of these children. Results demonstrated that both parents and health professionals identified support similarly in affective terms. Parents defined support as caring, and professionals identified it as being available to parents. Differences between the two groups were based on components of support identified as being more important. Parents identified affective behaviors such as caring, and instrumental support (i.e., assistance with childcare) as most important. Health professionals identified affective behaviors (i.e., caring) and educational support as most important (Williams, 1992). This study utilized three components of House's (1981) conceptualization of social support - emotional, informational, and instrumental support, but did not include appraisal support.

The adverse impact on psychological adjustment from the stress of living with newly diagnosed cancer is hypothesized to be affected by perceived social support. In a study by Varni, Katz, Colegrove, and Dolgin (1994), 30 children with newly diagnosed cancer completed standardized assessment instruments measuring depressive symptoms, state anxiety, trait anxiety, social anxiety, general self-esteem, and perceived social support from classmates, parents,

teachers, and friends. Their parents completed a standardized assessment instrument measuring internalizing and externalizing behavior problems. Perceived classmate, parent, and teacher social support were correlated with psychological adjustment parameters in the direction of greater support predicting lower psychological distress and higher self-esteem. Hierarchical multiple regression analyses identified perceived classmate social support as the most consistent predictor of adaptation, providing evidence of the essential function of the social environment of the school setting in affecting the adjustment of children with newly diagnosed cancer (Varni et al., 1994).

Krishnasamy (1996) reported that social support has advantageous effects on a variety of individual outcomes, including physical health, mental well being, and social functioning, and yet, its character, meaning, and measurement are still being debated in the clinical research literature. This pilot study set out to identify, within a theoretical framework of the social support literature, supportive and unsupportive behaviors as perceived by eight hospitalized patients diagnosed with a hematological malignancy. The findings of the semi-structured interviews suggest emotionally supportive behavior patterns are the most frequently identified helpful interactions reported by individuals with cancer, followed by informationally supportive behavior. The most frequently identified nurse behaviors reported to be unsupportive were those perceived of as being devoid of an emotional component (Krishnasamy, 1996).

An investigation by Ellerton, Stewart, Ritchie, and Hirth (1996) used a descriptive exploratory design to describe social support in children with a chronic health condition and how children use social support in coping with everyday demands and demands related to their condition. Participants comprised 62 school-aged children (16 with diabetes, 16 with cystic fibrosis, 15 with spina bifida, and 15 with no chronic illness). Data were collected about their social support networks, the support functions provided by the networks and their satisfaction with support. The children also described the social support they received and their use of social support as a coping strategy in specific stressful situations. The healthy children had the largest support networks overall and the largest peer networks. Children with spina bifida had the smallest networks overall and the smallest number of peers in their networks. Healthy children reported more support overall than the children in the illness groups. Both the healthy children and the children with a chronic illness described school related issues such as grades as the main source of everyday stress. Children with a chronic condition also identified physical restriction related to the illness as the key illness-related stressor. Children with a chronic condition reported more stress and more support seeking in everyday stressful situations than in illness situations (Ellerton et al., 1996).

Williams et al. (1997) conducted a pilot study to evaluate nursing interventions for siblings of children with chronic illnesses. The authors described

three major etiological themes explaining sibling adjustment problems. These are a) lack of informational support, or insufficient parental communication with well siblings about their brother or sister's conditions; b) lack of emotional support, or siblings feeling emotionally isolated from their parents; and c) insufficient existing resources for providing siblings with informational, emotional, and instrumental support. They concluded these themes are suggestive of the nature and content of social support interventions that will help promote sibling adaptation (Williams et al., 1997).

Summary of Research Findings. Research on sibling adaptation to the childhood cancer experience has underemphasized the role of social support as a moderator of illness-related effects on siblings' psychosocial adaptation (Murray, 1995). The childhood cancer experience is a stressor that increases subjective feelings of stress by well siblings and leads to increased adjustment difficulties such as anger, depression, anxiety, and acting out behaviors (Murray, 1999a; Walker, 1988). Evidence gathered from a wide range of studies over a number of years suggests that social support plays an important role in maintaining health and mitigating the deleterious effects of stress associated with the illness experience. Specifically, increased social support has been related to reductions in mortality rates, adjustment difficulties, and the incidence of both mental and physical illnesses (Callaghan & Morrissey, 1993; Keeling, Price, Jones, & Harding, 1996; Langsford et al., 1997).

The beneficial effects of social support on health outcomes have been well documented in the research literature (Ellerton et al., 1996; Frank, 1996; Nelson, 1990; Smith et al., 1994; Turner, 1983; Veitel & Baumann, 1992). The findings from these studies provide evidence of how social support is positively associated with adaptation to the illness experience. These findings are significant for the pediatric nurse planning nursing interventions to provide social support to siblings of children with cancer. Nursing interventions should focus on strategies to provide social support that enhance a sibling's adaptation to illness experiences during childhood (Murray, 1995; Williams et al., 1997).

Types of social support that are relevant to sibling adjustment include emotional support, informational support, instrumental support, and appraisal support (Cobb, 1976; Cohen, 1985; Havermans & Eiser, 1994; House, 1981; Kramer, 1981; Murray, 1995; Walker et al., 1992). The most comprehensive conceptual framework to study all four components of social support is that described by House (1981). The far-reaching aspects of social support identified by House (1981) bring together many dimensions of support that can be provided by nurses working with siblings of children with cancer. Because a paucity of research has evaluated social support and its impact on children and adolescents, additional research is needed to gain an enhanced awareness of the role of social support in moderating the effects of the stressors associated with the childhood cancer experience on well siblings (Murray, 1999a). In this study, the Nurse -

Sibling Social Support Questionnaire (NSSSQ) will be used to assess siblings' perceptions of nursing interventions that are helpful in adjusting to the childhood cancer experience and to determine how frequently these interventions are made available to them. This measurement tool, based on House's (1981) conceptualization of social support, includes items measuring the emotional, instrumental, informational, and appraisal components of support. Research aimed at identifying what interventions siblings of children with cancer perceive as supportive would be of immense value to determine what social support interventions siblings believe are helpful in adjusting to the childhood cancer experience (Murray, 1999a).

By determining support variables that may have a moderating effect on sibling well being, researchers can implement programs that will lead to enhanced coping. Understanding what social support interventions siblings of children with cancer perceive as being helpful is the first step in developing such programs. The results of this study can be used to design a future social support intervention for siblings of children with cancer.

Self-Concept and Siblings of Children With Cancer

To date, there is a dearth of clinical research investigating self-concept as it relates to children with cancer, childhood cancer survivors, and siblings of children with cancer (South, 1995). In 1995, South investigated perceived social support and self-concept of school age children diagnosed with leukemia. With a

sample of 17 school-age children, South utilized the Piers Harris Self Concept Scale and the Personal Resource Questionnaire. Results showed that the school-age children with leukemia, with lower levels of perceived social support, were more likely to have lower self-concept when compared to children with higher perceived support. The researcher also found a strong positive relationship between social support and self-concept of school age children with leukemia ($r = 0.545$, $p = 0.012$) (South, 1995). These results were supported by previous research that reported self-concept as being highly related to social support (Roberts, 1988). This research suggests that social support may play an important function in coping with the diagnosis of a childhood malignancy and the associated treatment modalities (South, 1995).

Beddell, Giordani, Amour, Tavormina, and Boll (1977) investigated the relationship of self-concept and stresses faced by chronically ill children. Subjects for the study were 45 chronically ill children between the ages of 6 and 15. The children were not in an acute phase of their illness. Types of the chronic illnesses of the subjects were cancer, asthma, cystic fibrosis, diabetes, hearing impairment, blindness, and different types of disabilities. Research instruments utilized included the Piers-Harris Children's Self-Concept Scale. The investigators found that children with fewer life stressors had a more positive self-concept. This group of children also experienced fewer health problems than children with higher stress levels. The investigators concluded that the presence of chronic illness

during childhood increases the risk and vulnerability of children to the stressors of life (Beddell et al., 1977).

In 1980, two psychologists investigated how chronically ill children, as well as a control group of healthy children, scored on a measure looking at self-concept (Burns & Zweig, 1980). Burns and Zweig (1980) utilized a projective technique where children were asked to perform a drawing task. The Draw-A-Face Test consists of 25 pages of pictures representing groups of children performing various tasks. The faces on the children are unmarked and the participants are asked to draw in the face of the child which the child believes to be most like himself/herself. The purpose of the Draw-A-Face Test is to obtain a forced choice measure of the child's self-concept on personality dimensions such as independence-dependence, passivity-activity, and extroversion-introversion. Subjects for the study consisted of 54 chronically ill children with diagnoses of leukemia, neuroblastoma, and malignant lymphoma. The children in the chronically ill group ranged in age from 3 ½ to 12 years. The control group consisted of 115 healthy children ranging in age from 3 ½ to 10 ½ years (Burns & Zweig, 1980).

Results of the investigation showed there were no significant differences between the Draw-A-Face Test scores for the chronically ill children and the control group. The researchers reported that the reason why differences were not found might have been related to response set bias. They recommended that

further research be conducted with the Draw-A-Face Test using a much larger and diverse sample of children. Furthermore, they advocated for factor analytic study of the Draw-A-Face Test responses in order to establish which aspects of the test are more sensitive to individual as well as group differences (Burns & Zweig, 1980).

In 1985, Carr-Gregg, White, Hughes, and Vowels evaluated the psychological effect of the childhood cancer experience on the self-concept and social adjustment of 40 children being treated for a pediatric malignancy. Instruments used for this investigation included the Piers-Harris Self-Concept Scale for Children as well as the Family Adjustment Scale. Results were compared to a group of healthy children matched for age, gender, socioeconomic status, and ethnic background. Outcomes from the study demonstrated a statistically significant relationship between self-concept scores and family adjustment scores. Seventy-two percent of the patient group scored well below published norms on the Piers-Harris Children's Self-Concept Scale. The investigators reported that demographic variables found to be associated with low Family Adjustment scores included age at onset of the cancer, socioeconomic status, amount of information given to families with respect to the type of cancer and prognosis, and the amount of distance between the family's home and the treatment facility. Ninety-two percent of families reported extreme economic problems related to having a child with cancer. The authors concluded by

emphasizing that the results of their study demonstrated the importance of performing psychosocial assessments on children with cancer and their families to identify families at risk for adjustment difficulties (Carr-Gregg et al., 1985).

Asada (1986) conducted the only study found on self-concept of siblings of children with cancer. The aim of this investigation was to explore specific factors in personality, family environment and family support systems that may effect the healthy siblings' adaptation to the childhood cancer experience. The convenience sample consisted of four girls and 2 boys ranging in age from 9 to 13 years. The ill siblings of these children were in their induction phase of treatment. The investigator hypothesized that the well siblings with more adaptive coping responses at the time of diagnosis and five weeks later as measured by the Child Behavior Checklist (CBCL), would have a higher level of self-concept as measured by the Self-Perception Profile for Children (SPPC); a low activity level as perceived by the parent on the CBCL; a perception of their family as cohesive and open to direct communication as measured by the Child version of the Family Environment Scale (CVFES); a supportive figure outside the family system as measured by a semi-structured interview. Each subject was administered the instruments and interviews individually. At the same time, their parents and teachers completed the CBCL. After five weeks, the well siblings were interviewed for a second time and their parents and school teachers completed a second CBCL measure (Asada, 1986).

Results of the study demonstrated that both parents and teachers identified that well siblings demonstrated some maladaptive coping responses (e.g., acting out behaviors, poor attention span in class, fear, anger, difficulty sleeping, and crying for unknown reasons). The siblings who had higher self-concept and perceived their families as open to communication seemed to have less difficulty adapting. The author reported that over time family cohesiveness appears to be significant to the positive adaptation of the well sibling to the childhood cancer experience. Clinical implications recommended by the researcher included providing informational support to siblings and encouraging parents to maintain the sibling's activities and contact with friends as much as possible. The sibling's need for normalcy and sense of belonging are important for the positive adjustment to the childhood cancer experience (Asada, 1986).

Benson (1987) conducted a quasi-experimental study to ascertain the association between a summer camping program and self-concept in children with cancer between the ages of 7 and 18. The sample consisted of 10 females and four males. Each subject served as his or her own control group in a pre-post test design. Before going to camp, the subjects completed the Piers-Harris Children's Self-Concept Scale and drew pictures with the instructions being to draw a picture of you and your friends doing something. Data analysis was accomplished using a t-test comparing the pre-camp and post-camp group means. Drawings were scored by a modified Kinetic Family Drawings Scale – Revised. Results of the statistical

analysis of the scores on the Piers-Harris Self-Concept Scale were not significant (.32, $p > .05$). Comparisons of the pre-camp and post-camp drawings were significant (.046, $p < .05$). The researcher reported that significant subscale scores were self-image (.027, $p < .05$) and emotional tone (.013, $p < .05$). The scores from the drawings suggested an improvement in self-concept resulting from the summer camping experience (Benson, 1987).

Finally, Dyson and Fewell (1989) investigated self-concept in siblings of disabled children as well as siblings of nondisabled children. The research participants were 74 children between the ages of 7 and 14. The researchers divided subjects into two groups: well children with disabled siblings and well children without disabled siblings. Furthermore, both groups were matched by gender, geographical locale (United States or Canada), socioeconomic status, and age within approximately 18 months. The study used the Piers-Harris Children's Self-Concept Scale to obtain a total self-concept score. Results demonstrated there was no statistically significant differences between siblings of children with disabilities and siblings of nondisabled children. ($p = .13$) (Dyson & Fewell, 1989).

Another interesting finding was the effects of attending support programs on the siblings' reported self-concept. The researchers found that self-concept of well siblings of disabled children, who attended support programs, did not vary in their level of self-concept from other siblings. The investigators hypothesized that

this finding may be attributed to the brief period of time well siblings spent in these programs as well as the infrequent offering of the group. The authors recommended that future studies be done with larger sample sizes and the use of multiple measures of self-concept to enhance the validity of findings (Dyson & Fewell, 1989).

Summary of Research Findings. Results of findings from the limited number of studies conducted on self concept as it relates to children with cancer, siblings of children with cancer, and children with chronic illnesses, demonstrates highly variable results. This is due in part to the limited number of reported studies and the small sample sizes. If an association between social support and self-concept is to be asserted, further studies examining self-concept and social support must be conducted to contribute empirical evidence for the evolution of interventions to prevent or minimize the incidence of adjustment difficulties in siblings of children with cancer.

Chapter III

Methodology

Chapter three provides an overview of the research methodology used for this study. The purpose, design, sample description, inclusion criteria, determination of sample size, setting, procedure, measures, risks to subjects, benefits to subjects, and statistical analysis are presented below.

Purpose

The purpose of this study was to investigate what social support interventions (emotional, informational, instrumental, appraisal support) school-age siblings of children with cancer currently receive, and what interventions they and their parents perceive as being helpful.

Design

A descriptive, exploratory design, which utilized the sibling and parent versions of the Demographic Information Data Sheet and the sibling and parent versions of the Nurse-Sibling Social Support Questionnaire (NSSSQ), was used to obtain information on siblings' and parents' perceptions of social support. The descriptive, exploratory approach was selected by the principal investigator as the most appropriate scientific approach for explicating the phenomena of social support for siblings of children with cancer. No research had been carried out to investigate siblings' perceptions of support compared with parents. Furthermore, social support had not been previously used directly with this population.

Sample

A nonprobability purposive sample for this study consisted of the school-age siblings and parents of children currently receiving treatment for childhood cancer. The sample was selected from a computerized census list of pediatric oncology patients currently undergoing treatment. A minimum age criterion of 7 years was imposed to maximize the ability of the sibling to participate in the study. The age of the sibling was limited to 7 to 12 years because children in this age group are in the cognitive developmental stage at which they can respond to questions independent of their parents' assistance (Piaget, 1969; Wong, 1995). School-age children have a level of conceptual understanding and developmental readiness to express answers to questions asked by adults (Flavell et al., 1993; Murray, in press b; Piaget, 1969). During the concrete operational stage (7 - 11 years) thought processes become increasingly logical and coherent. Children are organizing facts about their lives to use in problem solving. They are able to deal with a number of different aspects of a situation simultaneously and solve problems in a concrete, systematic fashion based on what they perceive (Flavell et al., 1993; Murray, in press b; Piaget, 1969).

School-age children begin to test the boundaries of social behavior, establish close friendships, and begin to develop a finely attuned sense of self-presentation. This is an age where the child develops a sense of proficiency, becomes increasingly competent and masters new skills (Erikson, 1963). The

school-age child takes pride in assuming greater responsibility and with increasing responsibility comes increasing self-esteem. The concrete operational stage marks the beginning of logical thought (Piaget, 1969). The school-age child is able to use deductive reasoning and to see relationships among various concepts (Flavell et al., 1993). True cooperation becomes possible because children are now able to differentiate their viewpoint from that of others, and they are able to value and respect both their personal autonomy and viewpoints and opinions of others (Flavell et al., 1993; Murray, in press b; Piaget, 1969).

School-age children as a group are beginning to explore ways in which they fit into social groups and society (Graue & Walsh, 1998). They are no longer just mere extensions of their parents. This developmental milestone of increased socialization allows children to be key informants in studies. Holmes (1998) points out that this landmark suggests an equality of relationship that is generally not feasible with younger children. Because children in this age group are able to read, write, think more logically, and interact more confidently with adults, they are more self-assured in social situations, and this self-confidence allows them to bridge the gap between researcher and child (Holmes, 1998). For these reasons, methods of gathering data can be extended to include the use of instruments (Murray, in press b).

In order to avoid confounding of measures, only one sibling in each family was included in the study. The target sibling was identified as the one nearest in

age to the child with cancer who fell within the age limits of the study. Studies uniformly show that siblings who are closer in age to the chronically ill child tend to experience more adjustment difficulties because of the close relationship they share (Boyce & Barnett, 1993; Lobato, 1990; McHale & Gamble, 1989).

Inclusion Criteria. Inclusion criteria for the siblings were as follows: siblings had to be 7 to 12 years of age, nearest in age to the child with cancer, have a brother or sister on active treatment for cancer for at least three months, live with the ill sibling and parent, and be fluent in English.

Inclusion criteria for the parent were as follows: parents had to be 19 years of age or older, the primary caregiver to the well sibling and child with cancer, live in the same household as the healthy and ill siblings, and be fluent in English.

Sample Size. For this study, t-tests were the statistical analyses used to compare data. The following results in Table 2, using the methodology described by Pedhazur and Schmelkin (1991), were from the pilot study conducted by the principal investigator using the sibling and parent versions of the Nurse-Sibling Social Support Questionnaire.

With an adjusted sample size of 40 in each group, the power increases to .80. A sample size of 40 in each group had a power of .80 and effect size of .63 at an alpha of .05. Oversampling was done by approximately 20% to account for any unforeseen difficulties with subjects during the research study. The final sample size of 50 includes the oversampling procedure.

TABLE 2. Estimation of Effect Size and Sample Size

	Mean	S.D.
Mothers (N=25)	120	10.39
Siblings (N=25)	112	13.00
<u>Power</u>	<u>Alpha</u>	<u>Effect Size</u>
.59	.05	.68

Setting

This study was conducted at a tertiary level military medical center that is the worldwide referral center for pediatric oncology patients and their families. In addition to caring for children of military dependents, this medical center cares for civilian children from a number of other countries as well as the United States. These children with special health care needs are designated as Secretary of the Air Force designees. Children with special health care needs include children who live in countries where appropriate oncology treatment options are not available or children from the United States who may not have access to advanced or experimental treatments for a number of reasons (i.e. insurance issues, lack of accessibility to treatment centers). In addition, this medical center is a member

of, and accredited by, the Pediatric Oncology Group (POG). In addition to having a pediatric oncology specialty, there is also a pediatric bone marrow transplant program that receives referrals from across the United States and internationally. The facility is located in the Southwestern portion of the United States and serves families from all branches of the armed forces.

Procedures

After obtaining approval for the study from The University of Texas at Austin and the medical center Institutional Review Boards, eligible families were identified and every eligible family was contacted by letter to explain the study. Eligible families were selected from a computerized census list of pediatric oncology patients currently undergoing treatment at the medical center located in the Southwestern portion of the United States. These families live (either permanently or temporarily) within a 20-mile radius of the medical center. Consent was obtained from parents and assent obtained from siblings. After consent and assent were attained, a sequential approach to the proposed study was undertaken with the open-ended questions preceding the questionnaire. The open-ended questions method was selected as the initial technique of data collection in this study since it was anticipated that completing the open-ended questions and questionnaire simultaneously would influence responses to each method. The qualitative questions provided an opportunity to explore in greater depth issues and concerns which could not be examined in the same detail in the questionnaire.

This study, using the Nurse - Sibling Social Support Questionnaire (NSSSQ), was carried out separately with parents and siblings. This study was conducted by the principal investigator in the pediatric oncology clinic during the well siblings summer vacation, weekends, and/or holiday school breaks during the fall (Appendix B). The study of siblings and their parents was conducted in separate rooms near the pediatric oncology clinic. The study room for the siblings was a children's lounge, decorated for children, located across from the pediatric oncology clinic. The room for parents was a parent lounge also located in the general vicinity of the clinic. Both areas had been used previously by the researcher for sibling and parent support groups. Both environments have been reported to be very quiet and non-threatening by group participants. The rooms were reserved in advance for the study to insure privacy.

Parents were asked to complete the demographic information data sheets and the parent version of the NSSSQ. Following completion of the questionnaires, the principal investigator answered questions and discussed any experiences the sibling or parent wanted to discuss.

Subject Recruitment and Enrollment. Eligible families of children with cancer were invited to participate in the study. The information letter (Appendix C) identified the purpose of the study and explained that individuals were being invited to participate. The letter included information about the process potential participants would be involved in, time commitments, potential risks, benefits,

and individuals the participants could call for questions they might have if they chose to participate in the study. Siblings participated after informed consent was obtained from parents. Then assent was obtained from siblings. Siblings were asked to participate in the study during weekends or school vacation when they were more likely to accompany their ill sibling to clinic or visit them in the hospital.

Protection of Human Subjects. Informed consent was obtained from parents and assent obtained from siblings (Appendix D). Parental consent for sibling participation was obtained before obtaining the sibling's assent. This study was not mentioned to the sibling until after the parent(s) agreed to participate. Since parental decision was absolute, this procedure respected parental authority and protected the child from going through a process that may have led to disappointment or a sense of powerlessness (Glantz, 1996; Grodin & Glantz, 1994; Murray, in press b). The consent and assent forms explained the purpose of the study, the participant's role in the study, and the fact that participation is voluntary. Participants were assured confidentiality and the right to withdraw from the study at any time. The consent and assent forms indicated that failure to participate would not influence the services they receive from the medical center or university.

Measures

Demographic Information Sheet. There are two demographic information data sheets that were obtained --one from the siblings and one from the parents. The Demographic Information Data Sheet - Sibling Version, (appendix E), is a questionnaire developed by the investigator for this study. Sample demographic information obtained included the following characteristics: (a) age of sibling, (b) position in family, (c) age of ill child, (d) sex of sibling, (e) sex of ill child, (f) specific diagnosis, (g) number of months between diagnosis and study, (h) treatment phase, (i) size of family, (j) marital status of parents, (k) availability of parent surrogates, (l) religion, (m) grade in school, and (n) ethnic background.

The Demographic Information Data Sheet - Parent Version, (Appendix F), is a questionnaire also developed by the investigator for this study. Sample demographic information obtained included the following characteristics: (a) age of parent, (b) caretaker status, (c) age of ill child, (d) age of sibling, (e) sex of sibling, (f) sex of ill child, (g) specific diagnosis, (h) number of months between diagnosis and study, (i) treatment phase, (j) size of family, (k) marital status, (l) availability of parent surrogates, (m) religion, (n) number of years of schooling, (o) ethnic background, (p) income, (q) education level, and (r) rank of active duty family member.

Instruments

Nurse - Sibling Social Support Questionnaire. There are two Nurse - Sibling Social Support Questionnaires: one for the siblings and one for the parents that examines their perceptions of social support for the sibling. The Nurse - Sibling Social Support Questionnaires (NSSSQ) (Appendix G & H) were developed by the investigator for this study. Based on House's (1981) conceptualization of social support, the instrument includes items measuring the emotional, instrumental, informational, and appraisal components of support. The instruments are 30-item, Likert scale instruments. The sibling version (Appendix G) is a self report measure asking siblings to indicate the extent to which they believe each of 30 nursing interventions help them with the childhood cancer experience and how frequently the interventions are made available to them by pediatric oncology nurses. At the end of the instrument are two open-ended questions which ask siblings to talk about what they wish nurses would do to help children who have a brother or sister with cancer. It also asks the siblings to discuss things that nurses or their parents have done that have been helpful. The parent version (Appendix H) of the instrument asks parents to report how helpful each of the 30 nursing interventions are to their well child, and how frequently the interventions are made available to the well sibling. Helpfulness ratings range from Not Helpful (1) to Extremely Helpful (5). Frequency ratings range from Never (1) to Always (5). The parent version also contains open-ended questions

that explore what they wish nurses would do to help children who have a brother or sister with cancer. It also asks the parents to discuss things they or nurses have done for siblings that have been helpful.

Development of the Nurse - Sibling Social Support Questionnaire. Much of the research done over the past 40 years has included recommendations of interventions to use in practice with siblings of children with cancer. These recommendations, along with suggestions from clinical experts in the field of pediatric oncology nursing, were used to develop the questionnaire. Process items defining types of social support were identified from these sources. These were evaluated in a small pilot study. Ten school-age siblings of children with cancer, their mothers, 10 pediatric oncology nurses, and 10 healthy school-age children were asked to complete and evaluate the instrument on clarity and appropriateness. As a result, new items were added to the instrument and previous items were revised (Murray, in press c).

Following this pilot study, five doctorally-prepared pediatric nursing faculty assisted as content experts. The 36 items were examined carefully for conceptual clarity, duplication, language level, clinical relevancy, and level of specificity, and the items were collapsed into 30 items defining the concept of social support for siblings of children with cancer. The revised instrument (NSSSQ) now includes 30 items assessing sibling and parent perceptions of supportive interventions (Murray, in press c).

The methodology described by Lynn (1986) was utilized to evaluate the content validity of the instrument. Determining the content validity index was performed by having the experts rate the content relevance of the instrument items using a 5-point ordinal rating scale, in which 1 indicated an irrelevant item, and 5 reflected an extremely relevant item (Murray, in press c).

All of the experts rated every item a 4 -5, indicating each item on the Nurse - Sibling Social Support Questionnaire was an indicator of a supportive intervention based on House's (1981) conceptualization of social support. The content validity index indicated 100% agreement among experts that items measured the concept of social support. The instrument items measuring components of emotional, informational, instrumental, and appraisal support are listed in Table 3.

TABLE 3. Instrument Items Measuring Components of Social Support

<u>Type of Support</u>	<u>Instrument Item Numbers</u>
Emotional Support	13, 16, 19, 20, 21, 24
Informational Support	2, 3, 6, 8, 9, 10, 14, 23, 25, 28, 29, 30
Instrumental Support	1, 11, 12, 17, 18, 22
Appraisal Support	4, 5, 7, 15, 26, 27

Pilot Testing of Instrument. In preparation for conducting this study, additional pilot testing of the tool was completed. Siblings and their mothers in the pilot testing of the instrument were recruited from two pediatric comprehensive cancer treatment centers located in Texas and Washington, D.C. Both centers belong to the Pediatric Oncology Group (POG). A total of 25 school-age children and their mothers participated in the study. Six children (24%) were 7 to 9 years of age and 19 children (76%) were 10 to 12 years of age. The siblings had brothers or sisters who were 6 to 62 months from the initial diagnosis of cancer, with a mean of 12.4 months. Sixty eight percent ($n = 17$) of the siblings had a brother or sister diagnosed with leukemia or lymphoma and 32% ($n = 8$) of the ill children had solid tumors. The age of mothers ranged from 20 - 39, with an average age of 29 years. All mothers graduated from high school, 32% ($n = 8$) had a college education. Eighty-four percent of the mothers ($n = 21$) did not work outside the home (Murray, in press c).

Following approval by the Institutional Review Board, data collection was completed over a 3-month period of time. Siblings and their mothers were identified as eligible for the study by the principal investigator after reviewing a computerized census list of pediatric oncology patients. Possible participants were discussed with the pediatric oncology nurse practitioner in each of the medical center settings. The principal investigator sent the family an information letter similar to the one for this study. Once interest was elicited, the study was

discussed with the mother and well sibling and informed consent and assent obtained. The sibling and mother completed the questionnaires in a private room in the pediatric oncology clinic setting. In addition, mothers completed the demographic information data sheets (Murray, in press c).

Descriptive Results. Using the sample of 25 school-age children and their mothers, internal consistency reliability was assessed by Cronbach's alpha. The internal consistency reliability for the sibling helpfulness scale was .92; the frequency scale was .90. Alpha coefficients for mother's were .94 for the helpfulness scale; .90 for the frequency scale. Owing to the small sample size, cautious interpretation of these results is indicated. These findings should be considered highly exploratory due to the sample size. Based on the reliability analysis, no items were reworded or eliminated (Murray, in press c).

In this study, scores for the helpfulness dimension on the NSSSQ for siblings ranged from 62 to 150 with a mean of 112. Scores for mothers ranged from 90 to 150 with a mean of 120. Frequency scores for siblings ranged from 38 to 90 with a mean of 62. Frequency scores for mothers ranged from 52 to 120 with a mean of 70. Examples of the most helpful interventions reported by both siblings and their mothers, and the type of support they provide, are shown in Table 4. Results indicated that sibling's perceptions of social support differ from

TABLE 4. Examples of the Five Most Helpful Social Support Interventions for Siblings

Mean	Intervention	Type of Support Provided
Sibling's Perception		
4.78	Help me to talk about my feelings	Emotional Support
4.74	Encourage my parents to spend time with me	Emotional Support
4.68	Help my parents to notice my good behaviors (i.e. achievements in school, sports etc.)	Emotional Support
4.53	Help my parents to get me involved in hobbies, school activities	Instrumental Support
4.40	Make sure the doctors/nurses include me when they plan how they are going to take care of my brother/sister	Instrumental Support
Mother's Perception		
5.00	Help my well child to talk about his/her feelings	Emotional Support
4.68	Encourage me to spend time with the other children in my family	Emotional Support
4.45	Teach my well child about cancer so he/she can understand what it is	Informational Support
4.39	Give my well child more information as he/she learns and understands more about cancer	Informational Support
4.33	Tell my well child about things that might happen to my ill child (e.g., while receiving chemotherapy, during hospitalizations etc.)	Informational Support

those of their mothers. Siblings perceive emotional and instrumental support as greater in importance, mothers perceive emotional support and informational support as more beneficial to siblings. Findings of this study suggest that there is a lack of congruency between perceptions of support by siblings and their mothers. There was minimal congruity between them in identifying which interventions were considered more supportive to the siblings (Murray, in press c).

Personal Attribute Inventory for Children. To begin to explore the validity of the Nurse-Sibling Social Support Questionnaire, discriminant construct validity testing was accomplished utilizing the Personal Attribute Inventory for Children (PAIC) (Appendix I). This 48-item adjective checklist is designed to measure children's self-concept. The focus of the PAIC is on evaluative and affective descriptions of the child's self. The PAIC has been tested on over 2500 children to date (Rasid & Parish, 1998). Initial psychometric testing was completed on over 1000 children (450 males and 586 females). The mean score on the PAIC for males was 12.01 with a standard deviation of 3.02. The mean score for females was 12.41 with a standard deviation of 2.75 (Parish & Taylor, 1978). The PAIC has recently been used to study relaxation training and student's level of anxiety (Rasid & Parish, 1998), relationships between college students' perceptions of their family members and how they interact with each other (Necessary & Parish, 1996), relationships of parents' perceived actions toward their children (Necessary

& Parish, 1995), behavioral adjustment and self-esteem of school-age children of women with breast cancer (Armsden & Lewis, 1994), parents actions as they relate to children's self-concepts (Parish & Necessary, 1994), the relationship between support system failures and college students' ratings of self and family (Parish, 1993), and perceived actions of parents and attitudes of youth (Parish & Necessary, 1993).

Scoring of the PAIC is done by asking the child to put an X on the line next to the 15 adjectives that best describe him or her. Twenty-four of the adjectives are positive and 24 are negative. The PAIC score is the total number of positive adjectives. Possible scores range from 0 to 15. The higher the score, the greater the child's self-concept (Parish & Taylor, 1978).

The PAIC has been shown to have good test-retest reliability. The subjects were 75 school-age children. Forty-seven (24 males and 23 females) were third grade students and 28 (11 males and 17 females) were sixth grade students. Based on four-week test-retest reliability coefficients for third grade students, the reliability of the PAIC was equal to .66 ($p < .001$). For sixth grade students, the reliability was equal to .87 ($p < .001$) (Parish & Taylor, 1978).

The same sample of forty-seven school-age children were included in the validity testing of the PAIC. Validity testing was accomplished by administering both the Personal Attribute Inventory for Children (PAIC) and the Piers-Harris Children's Self Concept Scale (PHSCS). A correlation of .67 ($p < .001$) was

detected between these two instruments. The validity coefficient indicates that the PAIC was moderately correlated with the concurrent criterion variable PHSCS. According to the researcher, the findings from the psychometric testing demonstrated that the PAIC is a reliable and valid measure of a general children's self-concept construct. In addition, the researcher reported that the instrument is easy to administer and to score providing a convenient alternative for evaluating children's self-concepts (Parish & Taylor, 1978).

Risks to Subjects

No major risks were anticipated to result from participation in this study. The potential risks for subjects included the following: (a) Some mothers and children may be uncomfortable sharing their feelings and concerns about certain questions with the researcher; and (b) some questions asked by the principal investigator may cause distress in the participants.

Minimizing Potential Risks. In order to reduce the potential risks for this study, if there was anything the parent or child did not wish to discuss, the principal investigator did not ask anything further about that question. A Child Life Specialist and/or Pediatric Social Worker with experience in pediatric oncology was available for consultation as needed. The subjects' confidentiality was maintained by use of coded questionnaires. The subjects could not be identified by name in any way. The names of the subjects were not used in any

report or scholarly presentation. All questionnaires were kept in a locked file cabinet accessible only to the investigator.

Potential Benefits to Subjects

Subjects may directly benefit from participating in this study by developing insight into their thoughts and feelings about the topic under investigation. Participation in this study may provide a therapeutic opportunity for the siblings and their parents to express those thoughts and feelings.

Statistical Analysis

This exploratory descriptive study used descriptive statistical analyses, the paired t-test (for ranking the difference between the paired scores), and simple regression analyses to address each of the research questions. The statistical package for the social sciences (SPSS) was used to analyze data.

Data Preparation. To facilitate the actual data entry process, edge coding was used where the margins on the instrument were used to write the appropriate numerical codes for the data (Polit & Hungler, 1995). The data was entered onto a computerized data file using a database program. Verification of the data input was done by checking the data input against raw data and by careful evaluation of the ranges for each variable in the study.

Data Analysis. The demographic information data sheet was analyzed using measures of central tendencies. These descriptive statistics were used to describe the subjects.

The major research questions for the study were as follows:

- (1) What social support interventions do school-age siblings of children with cancer perceive as being helpful?
- (2) What types of social support interventions do school-age siblings of children with cancer currently receive?
- (3) What social support interventions do parents of school-age siblings of children with cancer perceive as being helpful for their well children?
- (4) What types of social support interventions do parents of school-age siblings of children with cancer think their well children currently receive?
- (5) What are the differences between school-age sibling's and parent's perceptions of social support interventions?
- (6) What variables best predict school-age sibling's perceptions of helpful interventions based on total scores from the NSSSQ?

Questions 1 through 4 were evaluated using descriptive statistical analyses to look at each item score. Group means for degree of helpfulness and frequency of use were computed for both siblings and mothers. Mean tables were developed to look at the average degree of reported helpfulness and frequency of use of each of the 30 nursing intervention items of the Nurse - Sibling Social Support Questionnaires (NSSSQs). A rank order list of the most frequently reported helpful interventions, and interventions most frequently provided by pediatric oncology nurses, was created. The paired t-test, at the individual and group level,

was used to address question 5. The .05 significance level was chosen for the two-tailed significance test. Paired t-tests are indicated when the researcher is interested in obtaining measures from paired sets of subjects (Polit & Hungler, 1995). For this study, paired t-tests were used to test the difference between two sample means (the responses given by siblings and their parents). The assumptions of the t-test are as follows (Young & Veldman, 1981):

1. Scores in sample are independent of one another.
2. Samples come from a normal distribution.
3. The population standard deviation is unknown and the sample standard deviation is used.
4. Measurement scale is at least an interval scale.

Using the sibling version of the Nurse - Sibling Social Support Questionnaire, demographic information data sheet, and Personal Attribute Inventory for Children (PAIC) simple regression analyses were used to assess the relationship between the variables of: (a) age of subject, (b) gender of subject, (c) number of months between diagnosis and the present study, and (d) PAIC scores and Nurse - Sibling Social Support Questionnaire total scores. In simple regression, one independent variable is used to predict a dependent variable (Polit & Hungler, 1995).

To begin to explore the validity of NSSSQ, construct validity testing was accomplished utilizing the PAIC. A Correlation Coefficient was calculated using the total score from the PAIC and the total NSSSQ scores for siblings.

Utilizing the Nurse - Sibling Social Support Questionnaire, content analysis was used to address the responses to the open-ended question at the end of the instrument. Content analysis is commonly used to code responses to open-ended questions in research studies (Weber, 1988). Two coders independently classified the responses to the open-ended questions into categories of content. Themes were used to categorize the content into meaningful groups for this study. Both coders were provided with definitions of the four components of social support (emotional, informational, instrumental, and appraisal support) as defined by House (1981). Through this analysis the coders identified emerging themes that closely corresponded with the definitions of social support. Content validity for the classification of responses was calculated as a proportion of total agreement between the coders. Frequencies and percentages of the responses were calculated according to the components of support as defined by House (1981). The findings from this analysis were triangulated with the responses to the questionnaire to begin to explore the validity of the Nurse-Sibling Social Support Questionnaire. The subjects responses were used to illustrate the components of the NSSSQ found to be most helpful as perceived by the school-age siblings and their parents.

Triangulation in research has been defined as the combination of two or more theories, data sources, methods, or investigators in one study of a single phenomenon (Denzin 1989). Data (source) triangulation involves the use of multiple data sources with similar foci to obtain different views about the topic under investigation and for the purpose of validating findings (Begley, 1996; Kimchi, Polivka, & Stevenson, 1991). When using the strategy of data triangulation, the investigator explicitly attempts to maximize the range of data which might contribute to a more complete understanding of the topic being investigated (Knafl & Breitmayer, 1989; Murray, 1999b). Triangulation increases confidence in the results; allows development and validation of instruments and methods (confirmation); provides an understanding of the domain under investigation (completeness); is ideal for complex social issues; overcomes the elite bias of naturalistic research; and it allows divergent results to enrich explanation (Murray, 1999b; Redfern & Norman, 1994).

Assumptions

The major assumptions for the proposed study were as follows:

1. Participants would respond honestly to questionnaire items.
2. Participants would be able to accurately record and describe perceptions of social support needed by siblings.

3. Parents of children with cancer have different perceptions from their well children with regard to the type of interventions perceived to be helpful.
4. The goal of social support with respect to siblings of children with cancer is to facilitate optimal adjustment to the childhood cancer experience.

Limitations of Study

Limitations of the current study included:

1. The accuracy of the data was dependent on the willingness of the participants to respond honestly to questions on the self-report questionnaires and to understand the questions.
2. The generalizability of the results are limited by the fact that a convenience sample was used. In addition, results cannot be generalized to younger or older well siblings.
3. Child's developmental level was considered during the administration of the questionnaire. Although the study was designed to reduce problems related to the child's developmental stage, this did not preclude having children participate in the study that may be at a less advanced developmental stage.

Chapter IV

Findings

Chapter four provides an overview of the research results for this study.

The purpose of this study was to investigate what social support interventions (emotional, informational, instrumental, appraisal support) school-age siblings of children with cancer currently receive, and what interventions they and their parents perceive as being helpful.

Demographic descriptions of the study sample and findings of the most commonly reported helpful and frequently provided interventions are presented in this chapter. The results of individual and group level t-tests, correlations, and regression analyses are also presented.

Description of Subjects

Siblings. The subjects for this study were 50 school-age siblings of children with cancer and their primary caregiver. Well siblings ranged in age from 7 years to 12 years, with an average age of 9.58 (S.D. = 3.63). Fifty-four percent (n = 27) of the siblings were male and 46% (n = 23) were female. The majority of well siblings (68%, n = 34) were older than the child with cancer, while 32% were younger than the ill child. Most siblings (64%, n = 32) were in grades 3 through 5. Sixty-eight percent (n = 33) of siblings reported they had a surrogate parent (alternate caregiver), 67% (n = 22) of these surrogates were grandparents, 21% (n = 7) were Aunt/Uncles, and 12% (n = 4) were friends of the family. The majority

of the parent surrogates (50%) were available daily. When asked if the sibling had attended any support programs in the past year, 44% (n = 22) replied yes, 56% (n = 28) responded no. Demographics on the siblings are shown in Table 5.

TABLE 5. Demographic Characteristics of Siblings (n = 50)

<u>Characteristic</u>	<u>n</u>	<u>%</u>
<u>Age (years)</u>		
7	6	12%
8	7	14%
9	12	24%
10	9	18%
11	7	14%
12	9	18%
<u>Gender</u>		
Male	27	54%
Female	23	46%
<u>Sibling Order</u>		
Younger	16	32%
Older	34	68%
<u>Grade in School</u>		
1	3	6%
2	3	6%
3	9	18%
4	16	32%
5	7	14%
6	4	8%
7	8	16%

TABLE 5. (Continued)

Characteristic	n	%
<u>Parent Surrogate Availability</u>		
Yes	33	68%
No	17	32%
<u>Parent Surrogate Relationship to Sibling</u>		
Grandparent	22	67%
Aunt/Uncle	7	21%
Family Friend	4	12%
<u>Support During Past Year</u>		
Yes	22	44%
No	28	56%

Parents. Parents ranged in age from 27 years to 48 years, with a mean age of 37.88 (S.D. = 5.45). The majority (92%, n = 46) of the participating parents were mothers who were either married (70%, n = 35), separated (22%, n = 11) or divorced (8%, n = 4). All parents completed high school and 76% (n = 38) had some college education. Demographics on the parents are shown in Table 6.

Family. Family sizes ranged from 3 to 6 members with 4 being the average. Families were predominantly Non Hispanic/White (64%), followed by African American (16%), Hispanic (14%), Asian (2%), and multiracial (4%). The majority of the families were Catholic (48%). The remaining families were either

TABLE 6. Demographic Characteristics of Parents (n = 50)

Characteristic	n	%
<u>Age (years)</u>		
25 - 30	7	14%
31 - 35	9	18%
36 - 40	19	38%
41 - 45	11	22%
46 - 50	4	8%
<u>Gender</u>		
Female	46	92%
Male	4	8%
<u>Marital Status</u>		
Married	35	70%
Separated	11	22%
Divorced	4	8%
<u>Educational Level</u>		
High School	12	24%
Trade School/ Community College	10	20%
4 Year College	14	28%
Graduate School	14	28%

Protestant (34%), or practiced other religions (18%). Sixteen percent of families had annual incomes less than \$30,000, 84% greater than \$30,000. A review of the military status of the parents reveals that 50% were active duty officers, 30% were

enlisted, and 20% were retired from the military. Demographics on the families are shown in Table 7.

TABLE 7. Demographic Characteristics of Family (n = 50)

Characteristic	n	%
<u>Family Size</u>		
3	10	20%
4	24	48%
5	15	30%
6	1	2%
<u>Ethnicity</u>		
African American	8	16%
Non Hispanic/White	32	64%
Asian	1	2%
Hispanic	7	14%
Multiracial	2	4%
<u>Religion</u>		
Catholic	24	48%
Protestant	17	34%
Other	9	18%
<u>Income</u>		
Less than 20,000	1	2%
20,000 – 30,000	7	14%
31,000 – 45, 000	9	18%
More than 45,000	33	66%

TABLE 7. (Continued)

Characteristic	n	%
<u>Military Rank</u>		
Enlisted	15	30%
Officer	25	50%
Other	10	20%

III Child. The children with cancer in the families ranged in age from 4 years to 18 years, with an average age of 9.28 (S.D. = 3.63). Most (52%) of the ill children were males and 48% females. The majority of ill children, or 62% (n = 31), were diagnosed with leukemia, 16% (n = 8) with a brain tumor. The remaining 16% were diagnosed with Wilm's tumor (n = 2), Retinoblastoma (n = 1), Lymphoma (n = 2), Bone Tumor (n = 2), Rhabdomyosarcoma (n=3), or other malignancies (n = 1). Children who were in the maintenance phase of treatment constituted 96% (n = 48) of the ill child sample. The remaining 4% (n = 2) were undergoing induction for recurring disease. Seventy percent (n = 35) of the ill children were treated with chemotherapy, 2% (n = 1) had surgery, and 2% (n = 1) had a bone marrow transplant. An additional 26% (n = 13) had a combination of treatments. The average amount of time since diagnosis to the present study was 15.68 months. Forty percent (n = 20) of ill children were diagnosed in the past 12 months, 46% (n = 23) in the past 13 to 24 months, 12% (n = 6) in the past 25 – 36 months, and 2% (n = 1) in the past 37 – 48 months. Demographics on the children with cancer are shown in Table 8.

TABLE 8. Demographic Characteristics of Child with Cancer

Characteristic	n	%
<u>Age (years)</u>		
1 - 5	5	10%
6 - 10	31	62%
11 - 15	9	18%
16 - 20	5	10%
<u>Gender</u>		
Male	26	52%
Female	24	48%
<u>Diagnosis</u>		
Leukemia	31	62%
Brain Tumor	8	16%
Wilm's Tumor	2	4%
Retinoblastoma	1	2%
Lymphoma	2	4%
Bone Tumor	2	4%
Rhabdomyosarcoma	3	6%
Other	1	2%
<u>Treatment Phase</u>		
Induction	2	4%
Maintenance	48	96%
<u>Treatment</u>		
Chemotherapy	35	70%
Surgery	1	2%
Bone Marrow Transplant	1	2%
Combination Therapy	13	26%

TABLE 8. (Continued)

Characteristic	n	%
<u>Time Since Diagnosis (months)</u>		
1 – 12	20	40%
13 – 24	23	46%
25 – 36	6	12%
36 – 48	1	2%

Analysis of the Data

Research Question 1: What social support interventions do school-age siblings of children with cancer perceive as being helpful? A total sibling helpfulness score was calculated for all 30 items. The mean score for helpfulness of the total sibling sample was 118.92, with a standard deviation of 16.27. Descriptive statistics of the frequency of intervention helpfulness were computed and ranked for the entire sibling sample. The item mean scores representing helpfulness of the intervention ranged from 3.24 to 4.64 out of a total possible score of 5.00. The twelve most commonly reported helpful interventions were:

- (1) Encourage my parents to spend time with the other children in my family.
- (2) Help my parents to notice my good behaviors.
- (3) Help my parents to get me involved in hobbies, school activities.
- (4) Allow me to visit my brother/sister in the hospital.
- (5) Help me to talk about my feelings.

- (6) Help me to find others that can help me deal with having a brother/sister with cancer.
- (7) Provide assistance to my parents to help them meet the needs of the other children in our family.
- (8) Help me to attend support groups.
- (9) Teach community agencies about how they can help me with my brother's/sister's cancer.
- (10) Help my parents to balance family life so that the focus is not always on my ill brother/sister.
- (11) Give me honest responses to questions asked.
- (12) Include me in other family conferences when they talk about my brother/sister.

The interventions reported as being most helpful are directed at meeting the emotional and instrumental needs of well siblings. Table 9 rank orders the complete list of interventions reported by siblings of children with cancer to be most helpful.

Research Question 2: What types of social support interventions do school-age siblings of children with cancer currently receive? A total sibling frequency score was calculated for all 30 items. The mean score for frequency of the total sibling sample was 52.78, with a standard deviation of 26.49 suggesting considerable variability. Descriptive statistics of the occurrence of intervention

TABLE 9. Well Siblings' Ratings of Interventions Considered to be Most Helpful

Mean	S.D.	Rank Intervention	Support Provided
4.64	0.72	1. Encourage my parents to spend time with the other children in my family	Emotional
4.58	0.81	2. Help my parents to notice my good behaviors	Emotional
4.54	1.05	3. Help my parents to get me involved in hobbies, school activities	Instrumental
4.52	0.79	4. Allow me to visit my brother/sister in the hospital	Appraisal
4.44	1.05	5. Help me to talk about my feelings	Emotional
4.44	1.13	5. Help me to find others that can help me deal with having a brother/sister with cancer	Instrumental
4.42	0.78	6. Provide assistance to parents to help them meet the needs of other children in the family	Emotional
4.42	1.07	6. Help me to attend support groups	Instrumental
4.30	1.22	7. Teach community agencies about how they can help me with my brother's/sister's cancer	Instrumental
4.24	0.89	8. Help my parents to balance family life so that the focus is not always on my ill brother/sister	Emotional
4.24	0.85	8. Give me honest responses to questions asked	Appraisal
4.24	0.94	8. Include me in other family conferences when they talk about my brother/sister	Informational
4.20	1.18	9. Help me to talk to my brother's/sister's doctors/nurses and other hospital staff	Instrumental

TABLE 9. (Continued)

Mean	S.D.	Rank Intervention	Support Provided
4.18	1.08	10. Make sure the doctors/nurses include me when they plan how they are going to take care of my brother/sister	Instrumental
4.14	1.18	11. Take me to see the pediatric/pediatric oncology clinic	Appraisal
3.92	1.19	12. Help me to ask questions	Informational
3.84	1.13	13. Allow me to help with my brother's/sister's care	Appraisal
3.84	1.11	13. Include me in the first family conference at the time of diagnosis	Informational
3.82	1.34	14. Encourage my parents to discuss death with me	Informational
3.80	1.11	15. Help me to understand that I will not "catch" my brother's/sister's illness	Appraisal
3.72	1.34	16. Talk about death and dying with me	Informational
3.70	1.07	17. Help me to understand that I did not cause my brother's/sister's illness	Appraisal
3.52	0.93	18. Teach me about cancer so I can understand what it is	Informational
3.50	1.05	19. Tell me about things that might happen to my brother/sister	Informational
3.46	0.99	20. Help my parents to explain changes in the family system to me	Informational

TABLE 9. (Continued)

Mean	S.D.	Rank Intervention	Support Provided
3.44	0.93	21. Help my parents with anticipatory guidance	Emotional
3.36	0.94	22. Tell me about changes in my brother's/ sister's cancer	Informational
3.28	0.88	23. Give me more information as I learn and understand more about cancer	Informational
3.24	0.98	24. Tell my parents about new information on how brother's/sister's behave when they have a brother/sister with cancer	Informational
3.24	1.06	24. Give me books to help me better understand my brother's/sister's illness	Informational
Helpfulness Rating: 1 – Not helpful 4 – Very Helpful			
2 – Slightly Helpful 5 – Extremely Helpful			
3 – Helpful			

frequency were computed and ranked for the entire sibling sample. The item mean scores representing frequency of the intervention ranged from 1.16 to 3.24 out of a total possible score of 5.00. The five most frequently provided interventions were:

- (1) Allow me to visit my brother/sister in the hospital.
- (2) Take me to see the pediatric/pediatric oncology unit.
- (3) Give me honest responses to questions I ask.

(4) Help me to talk about my feelings.

(5) Help me to ask questions.

The interventions reported as being most frequently provided are directed at meeting the emotional, appraisal, and informational needs of well siblings.

Table 10 rank orders the complete list of interventions reported by siblings of children with cancer to be most frequently provided by nurses.

TABLE 10. Well Siblings' Ratings of Interventions Considered Most Frequently Provided by Nurses

Mean	S.D.	Rank Intervention	Support Provided
3.24	1.13	1. Allow me to visit my brother/sister in the hospital	Appraisal
3.06	1.20	2. Take me to see the pediatric/pediatric oncology unit	Appraisal
2.58	1.28	3. Give me honest responses to questions I ask	Appraisal
2.44	1.20	4. Help me to talk about my feelings	Emotional
2.02	1.20	5. Help me to ask questions	Informational
1.94	1.28	6. Help my parents to notice my good behaviors	Emotional
1.92	1.08	7. Teach me about cancer so I can understand what it is	Informational
1.88	1.04	8. Allow me to help with my brother's/sister's care	Appraisal
1.80	1.05	9. Tell me about things that might happen to my brother/sister	Informational

TABLE 10. (Continued)

Mean	S.D.	Rank Intervention	Support Provided
1.70	1.13	10. Encourage my parents to spend time with the other children in my family	Emotional
1.66	1.08	11. Tell me about changes in my brother's/sister's cancer	Informational
1.64	1.12	12. Provide assistance to my parents to help them meet the needs of the other children in our family	Emotional
1.60	1.05	13. Give me more information as I learn and understand more about cancer	Informational
1.54	1.13	14. Help my parents with anticipatory guidance for potential areas of difficulty with my adjustment to the childhood cancer experience	Emotional
1.50	1.04	15. Give me books to help me better understand my brother's/sister's illness	Informational
1.46	1.15	16. Help me to understand that I did not cause my brother's/sister's illness	Appraisal
1.46	1.01	16. Help me to talk to my brother's/sister's doctors/nurses and other hospital staff	Instrumental
1.44	0.86	17. Help my parents to explain changes in the family system to me	Informational
1.44	1.05	17. Make sure the doctors/nurses include me when they plan how they are going to take care of my brother/sister	Instrumental
1.42	1.13	18. Help me to understand that I will not "catch" my brother's/sister's illness	Appraisal
1.42	0.84	18. Help my parents to balance family life so that the focus is not always on my ill brother/sister	Emotional

TABLE 10. (Continued)

Mean	S.D.	Rank Intervention	Support Provided
1.38	0.95	19. Include me in other family conferences they have to talk about my brother/sister	Informational
1.34	0.82	20. Help my parents to get me involved in hobbies, school activities	Instrumental
1.32	0.82	21. Tell my parents about new information you find about how brothers/sisters behave when they have a brother/sister with cancer	Informational
1.32	0.84	21. Help me to find others that can help me deal with having a brother/sister with cancer	Instrumental
1.30	0.74	22. Help me to attend support groups	Instrumental
1.28	0.99	23. Include me in the first family conference at the time the doctors/nurses tell my parents my brother/sister has cancer	Informational
1.26	0.80	24. Talk about death and dying with me	Informational
1.20	0.81	25. Encourage my parents to discuss death with me	Informational
1.16	0.51	26. Teach community agencies about how they can help me with my brother's/sister's cancer	Instrumental
Frequency Rating:			
1 – Never			
2 – Seldom			
3 – Sometimes			
4 – Often			
5 – Always			

Summary. The interventions reported by well siblings as being most helpful are directed at meeting their emotional and instrumental needs. However, the data show that interventions made available by pediatric nurses are predominantly aimed at meeting sibling's needs for appraisal, informational, and/or emotional support. Interventions aimed at providing emotional support, and reported to be most helpful by well siblings, are some of the more frequently provided emotional support interventions.

Research Question 3: What social support interventions do parents of school-age siblings of children with cancer perceive as being helpful for their well children? A total parent helpfulness score was calculated for all 30 items. The mean score for helpfulness of the total parent sample was 119.56, with a standard deviation of 17.05. Descriptive statistics of the frequency of intervention helpfulness were computed and ranked for the parent sample. The item mean scores representing helpfulness of the intervention ranged from 1.90 to 4.74 out of a total possible score of 5.00. The ten most commonly reported helpful interventions were:

- (1) Help my well child to talk about his/her feelings.
- (2) Help my well child to ask questions.
- (3) Teach my well child about cancer so he/she can understand what it is.

- (4) Help me to notice good behaviors in my well child.
- (5) Tell my well child about things that might happen to my ill child.
- (6) Give my well child more information as he/she learns and understands more about cancer.
- (7) Allow my well child to visit my child with cancer in the hospital.
- (8) Encourage me to spend time with the other children in my family.
- (9) Give my well child honest responses to questions asked.
- (10) Help me with anticipatory guidance for potential areas of difficulty with my well child's adjustment to the childhood cancer experience.

The interventions reported by parents as the most helpful were directed at meeting the emotional and informational needs of well siblings. Table 11 ranks orders the complete list of interventions reported by parents as the most helpful for well siblings.

TABLE 11. Parents' Ratings of Interventions Considered to be Most Helpful

Mean	S.D.	Rank Intervention	Support Provided
4.74	0.72	1. Help my well child to talk about his/her feelings	Emotional
4.68	0.77	2. Help my well child to ask questions	Appraisal
4.68	0.77	2. Teach my well child about cancer so he/she can understand what it is	Informational
4.54	0.99	3. Help me to notice good behaviors in my well child	Emotional
4.54	0.81	3. Tell my well child about things that might happen to my ill child	Informational
4.48	0.89	4. Give my well child more information as he/she learns and understands more about cancer	Informational
4.48	0.93	4. Allow my well child to visit my child with cancer in the hospital	Appraisal
4.46	0.79	5. Encourage me to spend time with the other children in my family	Emotional
4.44	0.91	6. Give my well child honest responses to questions asked	Appraisal
4.42	0.76	7. Help me with anticipatory guidance for potential areas of difficulty with my well child's adjustment to the childhood cancer experience	Emotional
4.38	0.90	8. Tell me about new information you find about how brothers/sisters behave when they have a brother/sister with cancer	Informational
4.36	0.90	9. Help me to balance family life so that the focus is not always on my child with cancer	Emotional

TABLE 11. (Continued)

Mean	S.D.	Rank Intervention	Support Provided
4.28	1.07	10. Provide me with assistance to help them meet the needs of the other children in our family	Emotional
4.28	0.97	10. Take my well child to see the pediatric/pediatric oncology unit	Appraisal
4.20	0.95	11. Help my well child to understand that he/she will not "catch" my child's illness	Appraisal
4.20	1.05	11. Help my well child to understand that he/she did not cause my child's illness	Appraisal
4.18	1.08	12. Give my well child books to help him/her better understand my child's illness	Informational
4.06	1.02	13. Help me to explain changes in the family system to my well child	Informational
3.92	0.99	14. Tell my well child about changes in my ill child's cancer	Informational
3.74	1.10	15. Allow my well child to help with my ill child's care	Appraisal
3.68	1.32	16. Talk about death and dying with my well child	Informational
3.64	1.08	17. Help my well child to find others that can help him/her deal with having a brother/sister with cancer	Instrumental
3.54	1.36	18. Encourage me to discuss death with my well child	Informational

TABLE 11. (Continued)

Mean	S.D.	Rank Intervention	Support Provided
3.52	0.97	19. Help my well child to attend support groups	Instrumental
3.46	1.03	20. Help my well child to talk to my ill child's doctors/nurses and other hospital staff	Instrumental
3.36	1.22	21. Teach community agencies about how they can help my well child with my ill child's cancer	Instrumental
3.30	1.16	22. Help me to get my well child involved in hobbies, school activities	Instrumental
3.02	1.32	23. Include my well child in other family conferences they have to talk about my child with cancer	Informational
3.00	1.37	24. Make sure the doctors/nurses include my child when they plan how they are going to take care of my child with cancer	Instrumental
1.90	1.34	25. Include my well child in the first family conference at the time they tell my spouse & I our child has cancer	Informational
Helpfulness Rating: 1 – Not helpful			
2 – Slightly Helpful			
3 – Helpful			
4 – Very Helpful			
5 – Extremely Helpful			

Research Question 4: What types of social support interventions do parents of school-age siblings of children with cancer think their well children currently receive? A total parent frequency score was calculated for all 30 items. The mean score for frequency of the total parent sample was 59.94, with a standard deviation of 30.08. Descriptive statistics of the occurrence of

standard deviation of 30.08. Descriptive statistics of the occurrence of intervention frequency were computed and ranked for the parent sample. The item mean scores representing frequency of the intervention ranged from 1.28 to 3.24 out of a total possible score of 5.00. The eight most frequently provided interventions were:

- (1) Allow my well child to visit my child with cancer in the hospital.
- (2) Take my well child to see the pediatric/pediatric oncology unit.
- (3) Give my well child honest responses to questions asked.
- (4) Teach my well child about cancer so he/she can understand what it is.
- (5) Help my well child to talk about his/her feelings.
- (6) Help me to notice good behaviors in my well child.
- (7) Help my well child to ask questions.
- (8) Tell my well child about things that might happen to my ill child.

The interventions reported as being most frequently provided are directed at meeting the emotional, appraisal, and informational needs of well siblings.

Table 12 rank orders the complete list of interventions reported by parents to be most frequently provided by nurses.

TABLE 12. Parents' Ratings of Interventions Considered Most Frequently
Provided by Nurses

Mean	S.D.	Rank Intervention	Support Provided
3.24	1.30	1. Allow my well child to visit my child with cancer in the hospital	Appraisal
2.90	1.18	2. Take my well child to see the pediatric/ pediatric oncology unit	Appraisal
2.70	1.46	3. Give my well child honest responses to questions asked	Appraisal
2.50	1.34	4. Teach my well child about cancer so he/she can understand what it is	Informational
2.46	1.36	5. Help my well child to talk about his/her feelings	Emotional
2.36	1.56	6. Help me to notice good behaviors in my well child	Emotional
2.31	1.37	7. Help my well child to ask questions	Informational
2.14	1.32	8. Tell my well child about things that might happen to my ill child	Informational
2.08	1.45	9. Help my well child to understand that he/she will not "catch" my child's illness	Appraisal
2.08	1.47	9. Help my well child to understand that he/she did not cause my child's illness	Appraisal
2.08	1.21	9. Encourage me to spend time with the other children in my family	Emotional

TABLE 12. (Continued)

Mean	S.D.	Rank Intervention	Support Provided
2.06	1.27	10. Give my well child more information as he/she learns and understands more about cancer	Informational
2.06	1.25	10. Tell my well child about changes in my ill child's cancer	Informational
2.04	1.35	11. Help me with anticipatory guidance for potential areas of difficulty with my well child's adjustment to the childhood cancer experience	Emotional
2.02	1.20	12. Allow my well child to help with my ill child's care	Appraisal
1.98	1.12	13. Help me to balance family life so that the focus is not always on my child with cancer	Emotional
1.94	1.35	14. Tell me about new information you find about how brothers/sisters behave when they have a brother/sister with cancer	Informational
1.94	1.39	14. Give my well child books to help him/her better understand my child's illness	Informational
1.88	1.29	15. Make sure the doctors/nurses include my child when they plan how they are going to take care of my child with cancer	Instrumental
1.80	1.12	16. Help me to explain changes in the family system to my well child	Informational
1.80	1.05	16. Provide me with assistance to help them meet the needs of the other children in our family	Emotional
1.72	1.26	17. Help my well child to talk to my ill child's doctors/nurses and other hospital staff	Instrumental

TABLE 12. (Continued)

Mean	S.D.	Rank Intervention	Support Provided
1.70	1.31	18. Help my well child to find others that can help him/her deal with having a brother/sister with cancer	Instrumental
1.62	1.05	19. Include my well child in other family conferences they have to talk about my child with cancer	Informational
1.52	1.03	20. Help my well child to attend support groups	Instrumental
1.52	1.07	20. Help me to get my well child involved in hobbies, school activities	Instrumental
1.44	0.93	21. Teach community agencies about how they can help my well child with my ill child's cancer	Instrumental
1.40	0.86	22. Talk about death and dying with my well child	Informational
1.38	0.95	23. Encourage me to discuss death with my well child	Informational
1.28	0.86	24. Include my well child in the first family conference at the time they tell my spouse & I our child has cancer	Informational

Frequency Rating:

- 1 – Never
- 2 – Seldom
- 3 – Sometimes
- 4 – Often
- 5 – Always

Summary. The interventions reported by parents as being most helpful were directed at meeting the emotional and informational needs of well siblings. Furthermore, parents' perceptions of interventions made available to well siblings by pediatric nurses, were predominantly aimed at meeting their needs for emotional, informational, and appraisal needs.

A comparison of the rankings between siblings and parents for the most helpful and most frequently provided interventions are shown in Table 13 and 14 respectively. Note that parents and well siblings agree more closely on what interventions are provided than on what is helpful.

TABLE 13. Siblings' and Parents' Ranking of Most Helpful Interventions

Intervention	Ranking	
	<u>Siblings'</u>	<u>Parents'</u>
Encourage parents to spend time with other children in family	1	5
Help parents to notice sibling's good behaviors	2	3
Help parents to get sibling involved in hobbies, school activities	3	22
Allow sibling to visit brother/sister in the hospital	4	4
Help sibling to talk about feelings	5	1
Help sibling to find others that can help him/her deal with having a brother/sister with cancer	5	17
Provide assistance to parents to help them meet the needs of other children in the family	6	10
Help sibling to attend support groups	6	19
Teach community agencies about how they can help sibling with brother's/sister's cancer	7	21

TABLE 13. (Continued)

Intervention	Ranking	
	<u>Siblings'</u>	<u>Parents'</u>
Help parents to balance family life so that focus is not always on ill brother/sister	8	9
Give sibling honest responses to questions asked	8	6
Include sibling in other family conferences when they talk about brother/sister	8	23
Help sibling to talk to brother's/sister's doctors/nurses and other hospital staff	9	20
Make sure the doctors/nurses include sibling when they plan how they are going to take care of the ill brother/sister	10	24
Take sibling to see the pediatric/pediatric oncology clinic	11	10
Help sibling to ask questions	12	2
Allow sibling to help with brother's/sister's care	13	15
Include sibling in the first family conference at the time of diagnosis	13	25
Encourage parents to discuss death with sibling	14	18
Help sibling to understand that they will not "catch" brother's/sister's illness	15	11
Talk about death and dying	16	16

TABLE 13. (Continued)

Intervention	Ranking	
	<u>Siblings'</u>	<u>Parents'</u>
Help sibling to understand they did not cause brother's/sister's illness	17	11
Teach sibling about cancer so they can understand what it is	18	2
Tell sibling about things that might happen to brother/sister	19	3
Help parents to explain changes in the family system to sibling	20	13
Help parents with anticipatory guidance	21	7
Tell sibling about changes in brother's/sister's cancer	22	14
Give sibling more information as they learn and understand more about cancer	23	4
Tell parents about new information on how brother's/sister's behave when they have a brother/sister with cancer	24	8
Give sibling books to help them better understand brother's/sister's illness	24	12

TABLE 14. Siblings' and Parents' Ranking of Most Frequently ProvidedInterventions

Intervention	Ranking	
	<u>Siblings'</u>	<u>Parents'</u>
Allow sibling to visit brother/sister in the hospital	1	1
Take sibling to see the pediatric/pediatric oncology unit	2	2
Give sibling honest responses to questions	3	3
Help sibling to talk about feelings	4	5
Help sibling to ask questions	5	7
Help parents to notice siblings' good behaviors	6	6
Teach sibling about cancer so they understand what it is	7	4
Allow sibling to help with brother's/sister's care	8	12
Tell sibling about things that might happen to brother/sister	9	8
Encourage parents to spend time with the other children in family	10	9
Tell sibling about changes in brother's/sister's cancer	11	10

TABLE 14. (Continued)

Intervention	Ranking	
	<u>Siblings'</u>	<u>Parents'</u>
Provide assistance to parents to help them meet the needs of the other children in family	12	16
Give sibling more information as they learn and understand more about cancer	13	10
Help parents with anticipatory guidance	14	11
Give sibling books to help them better understand brother's/sister's illness	15	14
Help sibling to understand that they did not cause brother's/sister's illness	16	9
Help sibling to talk to brother's/sister's doctors/nurses and other hospital staff	16	17
Help parents to explain changes in the family system to sibling	17	16
Make sure the doctors/nurses include sibling when they plan how they are going to take care of ill brother/sister	17	15
Help sibling to understand that they will not "catch" brother's/sister's illness	18	9
Help parents to balance family life so that the focus is not always on ill brother/sister	18	13
Include sibling in other family conferences they have to talk about brother/sister	19	19

TABLE 14. (Continued)

Intervention	Ranking	
	<u>Siblings'</u>	<u>Parents'</u>
Help parents to get sibling involved in hobbies, school activities	20	20
Tell parents about new information you find about how brothers/sisters behave when they have a brother/sister with cancer	21	14
Help sibling to find others that can help them deal with having a brother/sister with cancer	21	18
Help sibling to attend support groups	22	20
Include sibling in the first family conference at the time the doctors/nurses tell parents brother/sister has cancer	23	24
Talk about death and dying with sibling	24	22
Encourage parents to discuss death with sibling	25	23
Teach community agencies about how they can help sibling's with brother's/sister's cancer	26	21

Research Question 5: What are the differences between school-age siblings and parents perceptions of social support interventions? The paired t-test, at the individual item and total score level, was used to address question 5. To control the overall Type 1 error rate at .05, Bonferroni's correction was used and

the significance level set at $p < .001$ for individual items only (Tabachnick & Fidell, 1996). There were no statistically significant differences on the total scores for helpfulness. However, there was a statistically significant difference on the total scores for frequency of social support interventions between the well sibling and parent groups (Table 15). Parents reported higher frequency of social support for their children than their children reported for themselves.

TABLE 15. Comparison of Total Helpfulness and Frequency Scores for Well Siblings and Parents

Scale	Well Siblings (n = 50)		Parents (n = 50)		t
	M	SD	M	SD	
Total Helpfulness	118.92	16.27	119.56	17.05	.23
Total Frequency	52.78	26.49	59.94	30.08	2.04 *

* $p < .05$.

The individual helpfulness scores were then examined to identify areas of difference between well siblings and parents. The statistically significant differences evident at the individual level for helpfulness were in the areas of informational support and instrumental support. Well siblings had higher mean scores on intervention items measuring instrumental support; parents had lower mean scores on these same items. Conversely, parents had higher mean scores on intervention items measuring informational support. Overall, there were no

significant differences on the majority of instrument items measuring emotional and appraisal support. A comparison of individual level helpfulness scores for well siblings and parents is displayed in Table 16.

TABLE 16. Comparison of Individual Level Helpfulness Scores for Well Siblings and Parents

	Well Siblings <u>(n = 50)</u>		Parents <u>(n = 50)</u>		
Intervention	M	SD	M	SD	<i>t</i>
<u>Emotional Support Items</u>					
Help sibling to talk about feelings	4.44	1.05	4.74	.72	2.09
Help parents to notice sibling's good behaviors	4.58	.81	4.54	.99	-.23
Help parents with anticipatory guidance	3.44	.93	4.42	.76	5.93*
Encourage parents to spend time with the other children	4.64	.72	4.46	.79	-1.18
Provide assistance to parents to help them meet the needs of the other children in family	4.42	.78	4.28	1.07	-.83
Help parents to balance family life	4.24	.89	4.36	.90	.80
<u>Informational Support Items</u>					
Include sibling in the first family conference	3.84	1.11	1.90	1.34	-8.53*
Include sibling in other family conferences	4.24	.94	3.02	1.32	-5.80*

TABLE 16. (Continued)

Intervention	Well Siblings (n = 50)		Parents (n = 50)		<i>t</i>
	M	SD	M	SD	
Teach sibling about cancer so they understand what it is	3.52	.93	4.68	.77	6.73*
Tell sibling about changes in ill brother's/sister's cancer	3.36	.94	3.92	.99	2.59
Give sibling more information as they learn and understand more about cancer	3.28	.88	4.48	.89	6.72*
Tell sibling about things that might happen to ill brother/sister	3.50	1.05	4.54	.81	5.55*
Help sibling to ask questions	3.92	1.19	4.68	.77	4.08*
Help parents to explain changes in the family system	3.46	.99	4.06	1.02	2.91
Talk about death and dying	3.72	1.34	3.68	1.32	-.15
Encourage parents to discuss death	3.82	1.34	3.54	1.36	-1.02
Give sibling books to help them better understand brother's/sister's illness	3.24	1.06	4.18	1.08	4.63*
Tell parents about new information found on how brothers/sisters behave when they have a brother/sister with cancer	3.24	.98	4.38	.90	6.16*

TABLE 16. (Continued)

	Well Siblings (n = 50)		Parents (n = 50)		
Intervention	M	SD	M	SD	<i>t</i>
<u>Instrumental Support Items</u>					
Include sibling when staff plans how they are going to take care of ill brother/sister	4.18	1.08	3.00	1.37	-4.27*
Help sibling to find others that can help them deal with having a brother/sister with cancer	4.44	1.13	3.63	1.08	-3.68*
Help sibling to talk to ill brother's/sister's doctors/nurses and other hospital staff	4.20	1.18	3.46	1.03	-3.22*
Help parents to get sibling involved in hobbies, school activities	4.54	1.05	3.30	1.16	-5.63*
Help sibling to attend support groups	4.42	1.07	3.52	.97	-4.97*
Teach community agencies about how they can help with brother's/sister's cancer	4.30	1.22	3.36	1.22	-3.74*
<u>Appraisal Support Items</u>					
Allow sibling to visit brother/sister in the hospital	4.52	.79	4.48	.93	-.29
Take sibling to see the pediatric/pediatric oncology unit	4.14	1.18	4.28	.97	.88

TABLE 16. (Continued)

Intervention	Well Siblings (n = 50)		Parents (n = 50)		<i>t</i>
	M	SD	M	SD	
Allow sibling to help with ill brother's/sister's care	3.84	1.13	3.74	1.10	-.53
Give sibling honest responses to questions asked	4.24	.85	4.44	.91	1.28
Help sibling to understand they did not cause brother's/sister's illness	3.70	1.07	4.20	1.05	2.55
Help sibling to understand they will not "catch" brother's/sister's illness	3.80	1.11	4.20	.95	1.89

* $p < .001$

The individual intervention scores were examined to identify areas of difference between well siblings and parents for the frequency scale. Only four statistically significant differences were evident at the individual level for frequency, in the areas of informational, emotional, and appraisal support. Parents had higher mean scores than the well siblings on each of these items. Parents reported that siblings receive these interventions more frequently than siblings reported. A comparison of individual level frequency scores for well siblings and parents is displayed in Table 17.

TABLE 17. Comparison of Individual Level Frequency Scores for Well Siblings and Parents

	Well Siblings (n = 50)		Parents (n = 50)		
Intervention	M	SD	M	SD	t
<u>Emotional Support Items</u>					
Help sibling to talk about feelings	2.44	1.20	2.46	1.36	.10
Help parents to notice sibling's good behaviors	1.94	1.28	2.36	1.56	2.10
Help parents with anticipatory guidance	1.54	1.13	2.04	1.35	3.24
Encourage parents to spend time with the other children	1.70	1.13	2.08	1.21	2.52
Provide assistance to parents to help them meet the needs of the other children in family	1.64	1.12	1.80	1.05	1.14
Help parents to balance family life	1.42	.84	1.98	1.12	4.16*
<u>Informational Support Items</u>					
Include sibling in the first family conference	1.28	.99	1.28	.86	0.00
Include sibling in other family conferences	1.38	.95	1.62	1.05	2.37
Teach sibling about cancer so they understand what it is	1.92	1.08	2.50	1.34	3.38*
Tell sibling about changes in ill brother's/sister's cancer	1.66	1.08	2.06	1.25	2.60

TABLE 17. (Continued)

Intervention	Well Siblings (n = 50)		Parents (n = 50)		<i>t</i>
	M	SD	M	SD	
Give sibling more information as they learn and understand more about cancer	1.60	1.05	2.06	1.27	3.27
Tell sibling about things that might happen to ill brother/sister	1.80	1.05	2.14	1.32	2.02
Help sibling to ask questions	2.04	1.21	2.31	1.37	1.59
Help parents to explain changes in the family system	1.44	.86	1.80	1.12	3.17
Talk about death and dying	1.26	.80	1.40	.86	1.48
Encourage parents to discuss death	1.20	.81	1.38	.95	2.02
Give sibling books to help them better understand brother's/sister's illness	1.50	1.04	1.94	1.39	3.01
Tell parents about new information found on how brothers/sisters behave when they have a brother/sister with cancer	1.32	.82	1.94	1.35	4.44*
<u>Instrumental Support Items</u>					
Include sibling when they plan how they are going to take care of ill brother/sister	1.44	1.05	1.88	1.29	2.90

TABLE 17. (Continued)

Intervention	Well Siblings (n = 50)		Parents (n = 50)		<i>t</i>
	M	SD	M	SD	
Help sibling to find others that can help them deal with having a brother/ sister with cancer	1.32	.84	1.70	1.31	2.43
Help sibling to talk to ill brother's/ sister's doctors/nurses and other hospital staff	1.46	1.01	1.72	1.26	1.61
Help parents to get sibling involved in hobbies, school activities	1.34	.82	1.52	1.07	1.46
Help sibling to attend support groups	1.30	.74	1.52	1.03	2.04
Teach community agencies about how they can help with brother's /sister's cancer	1.16	.51	1.44	.93	2.82
<u>Appraisal Support Items</u>					
Allow sibling to visit brother/ sister in the hospital	3.24	1.13	3.24	1.30	0.00
Take sibling to see the pediatric/ pediatric oncology unit	3.06	1.20	2.90	1.18	-.96
Allow sibling to help with ill brother's/sister's care	1.88	1.04	2.02	1.20	.89
Give sibling honest responses to questions asked	2.58	1.28	2.70	1.46	.75

TABLE 17. (Continued)

Intervention	Well Siblings (n = 50)		Parents (n = 50)		t
	M	SD	M	SD	
Help sibling to understand they did not cause brother's/sister's illness	1.46	1.15	2.08	1.47	4.19
Help sibling to understand they will not "catch" brother's/sister's illness	1.42	1.13	2.08	1.45	3.87*

* $p < .001$

Summary. The individual intervention scores examined to identify areas of difference between well siblings and parents demonstrated a statistically significant difference at the individual item level for helpfulness in the areas of informational support and instrumental support. Well siblings had higher mean scores on items measuring instrumental support; parents had higher mean scores on items measuring informational support. The few statistically significant differences evident at the individual level for frequency were in the areas of informational, emotional, and appraisal support. Overall, parents had higher mean scores than the well siblings on each of these items with the exception of one which was not statistically significant. Parents perceive that siblings receive these interventions more frequently than siblings report.

Research Question 6: What variables best predict school-age sibling's perceptions of helpful interventions based on total scores from the NSSSQ? A series of simple regressions were computed. The variables used to predict NSSSQ total helpfulness scores were: (a) age of sibling subject, (b) gender of sibling subject, (c) number of months between diagnosis and the present study, and (d) PAIC scores. The findings revealed no statistically significant results for any of the predictor variables. It is important to note that this analysis is somewhat underpowered because of the sample size. These results are displayed in Tables 18 and 19.

TABLE 18. Correlation of Variables Predicting Total Sibling Helpfulness Scores
(n = 50)

Variable	Total Sibling Helpfulness Scores
Sibling Age	-.12
Sibling Gender	.27*
Months Since Diagnosis	-.02
PAIC Score	-.27

$p > .05$

* Point-biserial Correlation

n = 50 well siblings

TABLE 19. Interrelations among Selected Variables

<u>Selected Variables</u>			
	Sibling Age	Sibling Gender	Months Since PAIC Score Diagnosis
Sibling Age		-.08	.36
Sibling Gender			.12*
Months Since Diagnosis			-.10
PAIC Score			

$p > .05$

* Point-biserial Correlation

n = 50 well siblings

Content Analysis. In the open-ended question, siblings were asked to "talk about things they wish nurses or parents would do to help children who have a brother or sister with cancer." Parents were asked to "talk about things they wish nurses would do to help children who have a brother or sister with cancer." For the sibling group, a total of 43 responses resulted from analysis of data. The main responses identified from the text data corresponded with the definitions for emotional and instrumental support. Nearly 42% (n=18) of the sibling responses were congruent with the definition of emotional support. For example, one 11-year-old sibling of a child with cancer reported, "Sometimes I think people forget about me. I wish people would pay more attention to me." Another sibling

included, "I wish my mother would hug me a lot like she did before my brother got sick. Sometimes I feel like she forgets about me."

Following the responses supporting the need for emotional support, 12 (28%) of the well siblings noted responses parallel to the definition for instrumental support. In one instance, a 10-year-old brother of a child with Ewing's Sarcoma wrote, "Sometimes I just want to be around my friends and do things that make me forget about the cancer for a while but I don't have anyone to take me to my friend's house because my mother and father are never home." One more sibling reported, "I wish there was a place for me to talk with other kids that have a brother with cancer. I want to know my brother will be all right."

After emotional and instrumental support, almost 21% ($n = 9$) of school-age siblings answered the open-ended questions with responses similar to the definition for informational support. An 11-year-old sibling wrote, "Everyone says they will tell me what cancer is and how it makes you lose your hair but they only tell me a little. I want to know more. I want to know what is going to happen to my sister in the future. Someone at school told me that chemotherapy makes you lose your memory. Will my sister remember me later?" One 8-year-old brother suggested, "Nurses should tell me if I can catch cancer. Sometimes I worry about that."

Finally, four (9%) of the responses met the definition of appraisal support. For example, one sibling of a child with a brain tumor reported, "If I could help

with my sister's central line I think I would not be so afraid of it." Another sibling indicated, "I wish my parents would let me out of school to go to my sister's appointments so I would know what was happening at the hospital."

In summary, the results of the content analysis for siblings support the quantitative findings of the NSSSQ. Well siblings repeatedly report interventions aimed at meeting their needs for emotional and instrumental support as being more helpful in adjusting to the childhood cancer experience. Results of the content analyses for well siblings are illustrated in Table 20.

TABLE 20. Characteristics of the Content Analysis Responses for Siblings (n = 43)*

Themes	n	%
Emotional	18	42
Informational	9	21
Instrumental	12	28
Appraisal	4	9
Total	43	100

*Note: The n is equal to the number of themes, not children.

For the parent group, a total of 65 responses resulted from analysis of data. The main responses identified from the text data corresponded with the definitions for emotional and informational support.

Sixty percent ($n = 39$) of responses from the parent data reflected the definition of emotional support. Examples of responses from parents reflecting emotional support included, "Nurses should develop personal relationships with the well children the same way they do with the child with cancer and the parents of that child. My husband and I find the nurses to be very supportive of our child and us. However, they don't spend as much time with our well children during clinic visits and hospitalizations." "The nurses and doctors should try to be a little lighthearted and less serious when the other children in the family are around. Our well children are constantly faced with seriousness." "Perhaps the most important thing that nurses can do for my well sons is to show an interest in them. By taking the time to learn their names, recognizing them when they come into the hospital or clinic, and asking them how their day was they help to make my sons feel important as well." Another parent of a child with neuroblastoma reported, "Pediatric nurses working with children with cancer should do everything possible to involve well children so they feel like they are getting attention as well." The reality of the situation for well siblings was best articulated by one mother of a child recently diagnosed with leukemia, "It seems that the nurses don't have the time for my other children just like my husband and I don't. This concerns me. Who should we ask to help? We don't have family in the area."

Following the large number of responses matching the definition of emotional support, were responses corresponding to the definition for

informational support. Twenty percent ($n = 13$) of the responses for mothers and fathers were congruent with the definition of informational support. One mother poignantly reported, "I think it is important to tell the well children about the cancer. It is not enough to give them just the basics. They should be told as much as they can understand. Parents should be honest in their responses to questions the well children asked. In our family, we tried to protect our well children by not sharing everything. In the end it was more difficult because our well children weren't sure that we were telling them everything. If we had to start over, we would be up front and honest." The father of one sibling wrote, "Nurses should spend more time teaching the well children about what is happening with the sick child. They should answer questions with appropriate words that the child can understand." Interestingly enough, one mother recognized the importance of information for her well children. However, she noted the time constraint placed on nurses when she reported, "There should be a Child Life Specialist to teach the well children about cancer. The nurses are too busy to teach both the parents and siblings."

Eleven of the 65 responses (17%) were accordant with the definition for instrumental support. The mother of a child with leukemia reported, "I don't have a lot of free time so it would be helpful if the nurses or social worker could help me find some community resources that are available for my well daughters. I heard there are support groups for the other children in families that have a child

with cancer but I haven't had the time to look for them. I think this would be helpful for my girls." Another mother reported the benefits of community resources for well siblings when she commented, "Attending special camps for healthy siblings has been helpful for my son. This experience helps him to feel like he is doing things like children his own age. I try every year to work with the social worker to plan for him to attend." Many parents remarked on the need for support programs for well siblings. For example, one father noted, "Nurses need to find a way to form support groups so the well children know they aren't alone and there are other kids with brothers and sisters with cancer." Another father criticized, "Support groups for siblings are extremely lacking! There should be a way for the siblings to get support during this very difficult experience."

Finally, only two (3%) responses reflected the definition of appraisal support. The mothers reported, "My healthy son is pretty nervous around my son with cancer. I think if he was included more in the daily treatment and care of the central line, he would be less nervous." The second mother noted, "I've taught my son how to draw up my daughter's medicine in a syringe. I think it's helpful for him to be involved. That way he doesn't imagine that bad things are always happening."

The frequencies and percentages found with the text data support the quantitative findings of the parent version of the NSSSQ. Parents report interventions aimed at meeting sibling's needs for emotional and informational

support as most helpful followed by instrumental and appraisal support. These findings further validate the quantitative portion of the instrument in that parents' perceptions of support are different than those of the siblings' perceptions. Results of the content analyses for parents are illustrated in Table 21.

TABLE 21. Characteristics of the Content Analysis Responses for Parents (n = 65)*

Themes	n	%
Emotional	39	60
Informational	13	20
Instrumental	11	17
Appraisal	2	3
Total	65	100

*Note: The n is equal to the number of themes, not parents.

Instrument Measures

Reliability. Using the sample of 50 school-age well siblings and 50 parents, internal consistency reliability was assessed by Cronbach's alpha. The internal consistency reliability for the sibling helpfulness scale was .91; the frequency scale was .98. Alpha coefficients for parent's were .92 for the helpfulness scale; .98 for the frequency scale. Reliability testing using Cronbach's alpha was also used for the four subscales of emotional, informational,

instrumental, and appraisal support. The internal consistency reliability for the sibling helpfulness emotional subscale was .80; informational subscale .82; instrumental subscale .87; and appraisal subscale .82. Alpha coefficients for the sibling frequency subscale were: emotional subscale .93; informational subscale .96; instrumental subscale .94; and appraisal subscale .87.

The internal consistency reliability for the parent helpfulness emotional subscale was .86, informational subscale .86; instrumental subscale .82; and appraisal subscale .82. Alpha coefficients for the parent frequency subscale were: emotional .92; informational .97; instrumental .95; and appraisal .90. Alpha coefficients of about .70 are usually considered acceptable in the early stages of instrument development, while higher alpha coefficients (at least .80) are generally more desirable (Burns & Grove, 1999). All alpha coefficients for this study were acceptable. The results are displayed in Table 22.

TABLE 22. Summary of Instrument Reliabilities

Subscale	Sibling (n = 50)	Parent (n = 50)
<u>Helpfulness Scale</u>		
Emotional Subscale	.80	.86
Informational Subscale	.82	.86
Instrumental Subscale	.87	.82
Appraisal Subscale	.82	.82

TABLE 22. (Continued)

Subscale	Sibling (n = 50)	Parent (n = 50)
<u>Frequency Scale</u>		
Emotional Subscale	.93	.92
Informational Subscale	.96	.97
Instrumental Subscale	.94	.95
Appraisal Subscale	.87	.90

Validity. To begin to investigate the validity of the Nurse-Sibling Social Support Questionnaire (NSSSQ), construct validity was estimated by correlating total NSSQ helpfulness and frequency scores for siblings with the Personal Attribute Inventory for Children (PAIC). A correlation of .27 ($p > .05$) was detected between the total sibling helpfulness score on the NSSSQ and the PAIC. The validity coefficient indicates that there was a small correlation between the NSSSQ sibling helpfulness scale and the PAIC scale. There was also a small correlation between the total sibling frequency score on the NSSSQ and the PAIC ($r = .20$, $p > .05$). Although the correlation for helpfulness approached significance ($p = .058$), the low correlation suggests the NSSSQ is measuring a different construct than the PAIC. The correlation for the frequency score did not approach significance ($p = .166$). Two-tailed significance tests were used for both.

To further explore content validity, content analysis was used to address the responses to the open-ended question at the end of the Nurse - Sibling Social Support Questionnaire. The questions asked the participants to write about things that they wish nurses would do to help children who have a brother or sister with cancer. The unit of analysis used to categorize the content into meaningful groups for this study was responses. A team of coders, the researcher and two independent coders, identified text data (responses) that closely corresponded with the definitions of social support used for this study. A content validity index for the classification of responses was calculated as a proportion of total agreement between the coders (Lynn, 1986). The content validity index indicated 100% agreement among coders that responses were categorized according to the appropriate definition of social support. Frequencies and percentages of the responses were then calculated. The subject's responses were used to illustrate the components of the NSSSQ found to be most helpful as perceived by the school-age siblings and their parents. As previously noted, findings from the content analysis support the quantitative findings. Siblings perceive emotional and instrumental support to be most helpful; parents perceive emotional and informational support to be most helpful.

Additional Findings

Independent sample t-tests were calculated to examine the differences between PAIC scores between school-age siblings who did and did not receive

support during the past year. The well siblings ($n = 22$) that received support during the past year attended a summer camp for siblings of children with cancer. Well siblings that received support during the past year scored higher on the PAIC than well siblings that did not attend camp (Table 23).

TABLE 23. Comparison of PAIC Scores and Well Siblings Support During Past Year

Scale	Siblings Receiving Support ($n = 22$)		Siblings Not Receiving Support ($n = 28$)		<i>t</i>
	M	SD	M	SD	
PAIC	13.14	0.99	11.14	2.53	3.480*

* $p < .001$.

Independent sample t-tests were also computed to explore the differences between well siblings who did and did not receive support during the past year and total scores on the NSSSQ helpfulness and frequency scales. As previously mentioned, the well siblings ($n = 22$) that received support during the past year attended a summer camp for siblings of children with cancer. There was a statistically significant difference between siblings that did and did not receive support on the frequency scale (Table 24).

TABLE 24. Comparison of NSSSQ Scores and Well Siblings Support During Past Year

Scale	Siblings Receiving Support (n = 22)		Siblings Not Receiving Support (n = 28)		t
	M	SD	M	SD	
Helpfulness Scale	119.86	16.49	118.18	16.36	.36
Frequency Scale	58.86	28.98	44.43	17.82	2.14*

* $p < .05$

Given the acceptably high alpha coefficients on the helpfulness and frequency subscales for the parent and sibling versions of the NSSSQ, additional analyses were done to examine differences on subscales between siblings that did and did not receive support during the past year. Independent sample t-tests were computed to explore the differences between well siblings who did and did not receive support during the past year and scores on the emotional, informational, instrumental, and appraisal subscales of the NSSSQ helpfulness and frequency scales. Using the helpfulness scale of the NSSSQ, there were no statistically significant differences on any of the subscales between siblings that did and did not receive support during the past year (Table 25).

TABLE 25. Comparison of NSSSQ Helpfulness Subscale Scores and WellSiblings Support During Past Year

Subscale	Siblings Receiving Support (n = 22)		Siblings Not Receiving Support (n = 28)		t
	M	SD	M	SD	
Emotional	26.00	3.46	25.57	3.24	.45
Informational	44.14	8.69	42.36	7.16	.79
Instrumental	25.96	5.62	26.18	5.07	-.15
Appraisal	24.09	3.82	24.36	4.98	-.21

$p > .05$

On the frequency scale of the NSSSQ, there was a statistically significant difference on the emotional support subscale. Siblings that attended a summer camp for well siblings, scored higher on the emotional support subscale. Using a one-tailed significance test, all four subscales were statistically significant (Table 26).

Additional t-test comparisons of well sibling and parent NSSSQ scores utilizing the subscales were also performed. Results demonstrated there was one statistically significant difference on the NSSSQ Helpfulness Scale. Well siblings scored higher on the instrumental support subscale (Table 27).

TABLE 26. Comparison of NSSSQ Frequency Subscale Scores and Well Siblings Support During Past Year

Subscale	Siblings Receiving Support (n = 22)		Siblings Not Receiving Support (n = 28)		t
	M	SD	M	SD	
Emotional	12.91	6.44	8.93	4.61	2.56*
Informational	21.32	12.63	16.07	6.55	1.90**
Instrumental	9.36	5.64	6.96	2.95	1.94**
Appraisal	15.14	5.90	12.46	4.70	1.78**

* $p < .05$ Two-Tailed Significance Test ** $p < .05$ One-Tailed Significance Test

TABLE 27. Comparison of NSSSQ Helpfulness Subscale Scores for Well Siblings and Parents

Subscale	Well Siblings (n = 50)		Parents (n = 50)		t
	M	SD	M	SD	
Emotional	4.29	.44	4.46	.16	.98
Informational	3.59	.31	3.92	.81	1.11
Instrumental	4.35	.14	3.38	.22	-11.71*
Appraisal	4.04	.31	4.22	.27	1.89

* $p < .001$

On the NSSSQ Frequency Scale, there were statistically significant differences between well siblings and parents on the emotional, informational, and instrumental support subscales. Parents had higher mean scores on all three subscales indicating they perceived that well siblings received these support interventions more frequently than siblings reported (Table 28).

TABLE 28. Comparison of NSSSQ Frequency Subscale Scores for Well Siblings and Parents

Subscale	Well Siblings (n = 50)		Parents (n = 50)		t
	M	SD	M	SD	
Emotional	1.78	.37	2.12	.25	4.00*
Informational	1.53	.27	1.87	.38	6.48**
Instrumental	1.33	.11	1.63	.17	7.29**
Appraisal	2.27	.80	2.50	.52	1.68

* $p < .05$

** $p < .001$

A series of multiple regression analyses were computed to investigate the simultaneous effects of four independent variables on the dependent variable NSSSQ total helpfulness score. The predictor variables used were (a) age of sibling subject, (b) gender of sibling subject, (c) number of months between diagnosis and the present study, and (d) PAIC scores. The multiple regression explained 11% of the variance in well sibling NSSSQ total helpfulness score

with sibling gender and PAIC scores emerging as significant predictors. The overall analysis was not significant at the .05 level ($p > .05$). These results are displayed in Tables 29, 30, and 31.

TABLE 29. Summary of Simultaneous Regression Analysis for Variables Predicting Sibling NSSSQ Total Helpfulness Scores (n = 50)

Variable	B	SEB	<i>B</i>	<i>p</i>
(Constant)	151.874	17.211		.000
Sibling Gender	10.144	4.439	.314	.027*
Sibling Age	-.978	1.386	-.102	.484
Months Since Diagnosis	-.066	.284	.034	.816
PAIC Score	-2.264	1.001	-.310	.029*

* $p < .05$

TABLE 30. Model Summary

Model 1	R	R Square	Adjusted R Square	Std. Error of the Estimate
	.426	.182	.109	15.36

a. Predictor Variables: (Constant), Sibling Gender, Sibling Age, Diagnosis Months, PAIC Score

b. Dependent Variable: Sibling Helpfulness Score

TABLE 31. ANOVA

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	2358.463	4	589.616	2.499	.056
	Residual	10617.217	45	235.938		
	Total	12975.680	49			

a. Predictor Variables: (Constant), Sibling Gender, Sibling Age, Diagnosis Months, PAIC Score

b. Dependent Variable: Sibling Helpfulness Score

Further multiple regression analyses were calculated to examine the concurrent effects of three independent variables on the dependent variable NSSSQ total helpfulness score. The predictor variables used were (a) age of sibling subject, (b) gender of sibling subject, and (c) PAIC scores. Removing the diagnosis months variable resulted in this model explaining 13% of the variance in well sibling NSSSQ total helpfulness score with sibling gender and PAIC scores once again emerging as significant predictors. Females had higher NSSSQ total helpfulness score than males. Furthermore, lower PAIC scores are associated with higher NSSSQ total helpfulness scores. The overall analysis was significant at the .05 level ($p = .03$). These results are displayed in Tables 32, 33, and 34.

TABLE 32. Summary of Simultaneous Regression Analysis for VariablesPredicting Sibling NSSSQ Total Helpfulness Scores

Variable	B	SEB	<i>B</i>	<i>p</i>
(Constant)	151.690	17.015		.000
Sibling Gender	9.990	4.345	.309	.026*
Sibling Age	-1.098	1.275	-.115	.394
PAIC Score	-2.233	.982	-.306	.028*

* $p < .05$ TABLE 33. Model Summary

Model 2	R	R Square	Adjusted R Square	Std. Error of the Estimate
	.425	.181	.127	15.20

a. Predictor Variables: (Constant), Sibling Gender, Sibling Age, PAIC Score

b. Dependent Variable: Sibling Helpfulness Score

TABLE 34. ANOVA

Model		Sum of Squares	df	Mean Square	F	Sig.
2	Regression	2345.569	3	781.856	3.383	.026*
	Residual	10630.111	46	231.089		
	Total	12975.680	49			

a. Predictor Variables: (Constant), Sibling Gender, Sibling Age, Diagnosis Months, PAIC Score

b. Dependent Variable: Sibling Helpfulness Score

* $p < .05$

Assumption Testing

Testing for normal distribution was completed using the Kolmogorov-Smirnov Test and histogram analysis of standardized residuals.

Kolmogorov-Smirnov Testing. The purpose of this test is to determine if the observed distribution is significantly different than the normal distribution (Pedhazur & Schmelkin, 1991). Results demonstrated the observed distribution of NSSSQ helpfulness and frequency scores was not significantly different than the normal distribution (Kolmogorov-Smirnov $Z = 1.240$, $p > .05$).

Histogram Analysis of Standardized Residuals. In addition, a histogram of the standardized residuals was utilized to visually assess if the dependent variable was normally distributed for every value of the independent variable. Results showed the distribution to be approximately normal. Although the data was slightly negatively skewed, the distribution does not significantly deviate from normal. Furthermore, using the central limit theorem, the sampling distribution tends to approach normality as the sample size approaches infinity (Pedhazur & Schmelkin, 1991; Tabachnick & Fidell, 1996).

Linearity. Linearity was examined for the regression analyses by inspecting the plot of standardized residual versus standardized predicted values. If both variables are normally distributed and related in linear fashion, the

scatterplot is oval in appearance (Tabachnick & Fidell, 1996). The model for this study is appropriate for the data. Furthermore, homogeneity of variance is tenable.

Independence. Observations between subjects were independent of one another.

Casewise Diagnostics. The following casewise diagnostics were examined to identify outliers: (a) standardized residuals, (b) centered leverage values, (c) Mahalanobis' distance, and (d) Cook's distance. Analysis of data revealed no outliers. Standardized residual scores fell within the range of -3.00 and 3.00 . Overall, 90% of scores fell within -2.00 and $+2.00$. A centered leverage value of 0.24 was calculated based on the number of predictor variables and sample size. Analysis of the data disclosed no outliers (values > 0.24). Mahalanobis' distance displayed no outliers on the predictor variables. Values ranged from 0.967 to 7.732 . The identified critical value was 14.18 . Cook's distance examined influential data points as a function of being an outlier on the side of the predictor or criterion variable. Values ranged from 0.000 to 0.183 . The critical value of 1.0 was not exceeded.

Summary

The findings and analysis of data for the study of social support for school-age siblings of children with cancer were presented in this chapter. Demographic data were analyzed utilizing descriptive statistics. Descriptive statistical analyses were also used to examine NSSSQ helpfulness and frequency

scores for both siblings and parents. Paired t-tests were used to test the difference between the responses given by siblings and their parents on the NSSSQ helpfulness and frequency scales. Regression analyses were chosen to determine variables providing the most predictive power for helpfulness scores of well siblings of children with cancer. A Correlation Coefficient was calculated using the total score from the PAIC and the total NSSSQ scores for siblings to further explore the validity of the Nurse-Sibling Social Support Questionnaire (NSSSQ). Finally, using the NSSSQ, content analysis was used to address the responses to the open-ended questions at the end of the instruments.

Results demonstrated that well siblings perceive interventions aimed at providing emotional and instrumental support to be most helpful. Parents perceive interventions aimed meeting the well siblings' needs for emotional and informational support to be most beneficial. Although there was no statistically significant difference on the overall total scores for helpfulness, there was a statistically significant difference on the overall total scores for frequency of social support interventions between the well sibling and parent groups. Furthermore, statistically significant differences at the individual level for helpfulness in the areas of informational and instrumental support did exist between well siblings and parents. Well siblings had higher mean scores on items measuring instrumental support; parents had higher mean scores on items measuring informational support. The few statistically significant differences

evident at the individual level for frequency were in the areas of informational, emotional, and appraisal support. Parents tended to have higher mean scores overall in each of these areas.

Independent sample t-tests exploring the differences between well siblings who did and did not receive support during the past year and scores on the emotional, informational, instrumental, and appraisal subscales of the NSSSQ helpfulness and frequency scales demonstrated there were no statistically significant differences on any of the helpfulness subscales. However, there was a statistically significant difference on the emotional support subscale of the frequency scale of the NSSSQ. Siblings attending summer camp for well siblings scored higher on the emotional support subscale. Furthermore, when one-tailed significance tests were completed, significance on the informational, instrumental, and appraisal subscale emerged.

Additional t-tests comparing well sibling and parent NSSSQ scores utilizing the subscales demonstrated there was one statistically significant difference on the NSSSQ Helpfulness Scale. Well siblings scored higher on the instrumental support subscale. On the Frequency Scale, parents had statistically significant higher mean scores on the emotional, informational, and instrumental subscales indicating they perceived that well siblings received these support interventions more frequently than siblings reported.

Simple regressions revealed no statistically significant results for any of the predictor variables. However, multiple regression analyses demonstrated that sibling gender and PAIC score emerged as significant predictors of NSSSQ Total Helpfulness Scores. The correlation coefficient indicated there was a small positive correlation between the sibling version of the NSSSQ and the PAIC scale suggesting the NSSSQ is measuring a related, but different construct than the PAIC. Results of the content analysis of the NSSSQ open-ended questions for siblings and parents support the quantitative findings of the NSSSQ. Well siblings reported interventions aimed at meeting their needs for emotional and instrumental support as being more helpful in adjusting to the childhood cancer experience; parents reported more interventions aimed at meeting well sibling needs for emotional and informational support.

Chapter V

Discussion

Chapter five provides a discussion of the study results in relation to the review of the literature. The findings highlight the need for pediatric health care professionals to recognize that children's perceptions of their own need for social support are not congruent with those of their parents and health care professionals. Recommendations for future use of the Nurse-Sibling Social Support Questionnaire are considered. In addition, recommendations for theory development, research, clinical practice, and education are discussed. Finally, some thoughts on self-concept and siblings of children with cancer are reviewed.

This study by the principal investigator examined what social support interventions (emotional, informational, instrumental, appraisal support) school-age siblings of children with cancer currently receive, and what interventions they and their parents perceive as being helpful in the siblings' adjustment to the childhood cancer experience. This study had a specific emphasis on the social support variables as described by House (1981).

Sibling Perceptions of Most Helpful Interventions

Interventions reported by well siblings as the most helpful were directed at meeting their needs for emotional and instrumental support. These findings are consistent with the pilot study results (Murray, in press c). The findings are also

consistent with those of other researchers. Havermans and Eiser (1994) found that siblings consistently reported the need to be cared for emotionally. The authors noted the most terrible thing well siblings remembered about the childhood cancer experience was being left out and not being able to share their feelings.

Oftentimes this disregard led the well siblings to be overly concerned about the uncertainties of the illness. Spinetta (1981) also reported that well siblings of children with cancer need to be emotionally cared about. The author recommended that health care professionals become aware of the needs of well siblings and regularly remind parents of the siblings' emotional needs. Spinetta (1981) recommended that siblings be given the opportunity to actively express their feelings and concerns about issues related to the childhood cancer experience. Kramer (1981) also noted that health care professionals and parents need to keep in mind the importance of expressing their valuation for the well sibling's commendable behaviors and cooperation during the illness experience. "Acknowledgement and praise will help the well sibling to feel loved, respected, and needed – for his/her unique contributions and for him/herself" (Kramer, 1981, pp. 164). This intervention will meet the well sibling's need for emotional support.

Wang and Martinson (1996) reported that although well siblings would like to talk about their feelings, they don't. Sixty percent of subjects ($n = 27$) reported they did not have the opportunity to discuss feelings with their parents.

Siblings noted that parents did not like to talk about the illness and there was no time to talk with parents. Only 40% of the siblings reported discussing the illness at all. When it was discussed, the focus was placed on how the ill child was doing (Wang & Martinson, 1996).

In analyzing comments from the open-ended questions from the NSSSQ, the need for emotional and instrumental support by well siblings was exceedingly evident. One 9 year-old brother of a child with leukemia reported, "Sometimes I think people forget about me. I wish people would pay more attention to me." Another sibling of a child with a brain tumor wrote, "I want someone to tell me that everything is going to be all right but it never happens." A different sibling, who also has a brother with a brain tumor, wrote how he felt when he did receive attention. "I feel really good when the nurses and doctors include me when they talk. I wish they would do this more. It makes me feel like I'm important too." Earlier findings by the researcher (Murray, 1998) support this data. The researcher found that well siblings report a greater need for emotional support, than any other type of support, during the childhood cancer experience.

The results of this study distinctly highlight the extraordinary importance siblings place on emotional support. It is also the researcher's experience in clinical practice, as well as with support groups for siblings of children with cancer, that siblings continuously seek out the emotional attention of others. This

study provides scientific evidence of the well siblings' paramount need for this type of social support.

When examining instrumental support, well siblings reported a heightened desire for things to return to normal, such as the way things were before their brother or sister became ill. A 10 year-old sister of a child with osteosarcoma reported, "All I remember about my sister's cancer is that I never have time to play with my friends. I wish I could do that more. I don't play with any of my best friends anymore." Another child with a sister with leukemia wrote, "I wish I could spend more time with my friends. When my sister is in the hospital I have to go to the neighbors and don't always get to see my friends." These findings are consistent with those of Harding (1996) who reported the need for well siblings to have normalcy in their lives – the chance to continue to participate in their social groups.

In the researcher's personal experiences in working with siblings of children with cancer, the overwhelming need for siblings to be with children their own age, and to be in an environment where they can just be a "normal" child, was evident. Siblings frequently ask to have additional support groups solely for the purpose to be with other children to share their feelings and to have an opportunity to participate in activities with others of the same age. Having a brother or sister with cancer limits opportunities to play with other children because of the restrictions having an ill sibling places on daily activities.

Sibling Perceptions of Frequently Provided Interventions

The interventions reported by well siblings as the most frequently provided are directed at meeting emotional, appraisal, and informational needs. Although the interventions may meet the well siblings' need for emotional support, they are not meeting their needs for instrumental support as frequently as siblings would like. These findings are supported by previous research of the researcher (Murray, 1995) and Walker et al. (1992), who found that pediatric oncology nurses most frequently provide interventions for well siblings based on meeting their needs for emotional and informational support. Other researchers also report health care professionals provide emotional and informational support to families with a child with cancer (Williams, 1992). All three researchers recommend that health care providers working with families of children with a pediatric malignancy should complete comprehensive assessments and evaluate each family member's need for additional types of support best suited for the individual's specific needs.

The current study emphasizes the need for nurses to re-evaluate why they provide the interventions they do for well siblings. Based on the researcher's experiences, pediatric nurses have historically provided interventions based on what they perceive to be helpful for the well siblings. This study contributes scientific evidence of the need for nurses to thoroughly appraise what siblings perceive as helping them adjust to having a brother or sister with cancer.

Parent Perceptions of Most Helpful Interventions

Parents of siblings of children with cancer perceive emotional support and informational support as more beneficial to siblings. These findings are consistent with pilot study data suggesting there is a deficit in correspondence between perceptions of support by siblings and their parents. There was minimal congruity between well siblings and parents in identifying which interventions were considered more supportive to the siblings (Murray, in press c). Interestingly, Williams (1992) found that parents reported the most important types of support that helped them deal with the childhood cancer experience were emotional and instrumental support. The author reported that parents rarely identified teaching or informational support as an important component of support. Parents consistently mentioned the need for instrumental support before informational support (Williams, 1992). However, when it comes to their well children, they perceive informational support as more beneficial than instrumental support. Parents' perceptions of what is helpful may be random and biased. This bias may be related to the parents' belief that the other types of support are already being met. This is significant because the parents and health care professionals determine the type of supportive interventions needed by well siblings (Murray, in press d, Walker, et al., 1992).

LaMontagne and Pawlack (1990) found that families of critically ill children need health care professionals to frequently assess what is supportive for

individual family members during the illness experience. Findings from this study are also applicable in the case of childhood cancer. Assessment of the well siblings' perception of support should be accomplished during the illness experience. Nurses, as well as parents, should reconsider how they assess sibling needs for support.

Additional research offered some valuable findings. Woodgate (1999b) and Enskar et al. (1997) found that parents, especially mothers, are a major determinant of the types of social support provided for school-age children and adolescents with cancer. Although, this research is nonspecific regarding the type of support provided by parents in the child's family system, other researchers have found that emotional support from parents was of primary importance to school-age children with cancer (Hockenberry-Eaton & Minick, 1994). In addition, support from friends is important to this group of children with cancer. However, many of these children with cancer do not receive the instrumental support needed (Hockenberry-Eaton & Minick, 1994).

The findings of this study are congruent with the researcher's clinical experience in working with families of children with cancer for 15 years. It is frequently the mothers who determine what type of support interventions well siblings take part in. Mothers decide whether or not siblings attend support groups and summer camps. Mothers ask for more assistance seeking interventions that will provide informational support than any other type of support. The researcher

has found that mothers believe they are meeting the other support needs of the well children in the family. Often when nurses are able to get parents, especially mothers, to focus on their well children for a brief period of time, parents recognize that they are not addressing the support needs of their healthy children.

A review of the qualitative responses to the open-ended questionnaire items support parent perceptions. One mother of a 7-year-old child with leukemia reported, "This is really sad to say, but sometimes I need to be reminded that I have other children to consider and that this cancer is affecting them as well." Another mother of a child also diagnosed with leukemia wrote, "Sometimes my husband and I need to remember that this is hard on our well son as well. When he acts up we get angry with him when we should understand that he is going through a rough time as well. Sometimes our thoughts are elsewhere and we just forget. Sometimes we need to be reminded that he has feelings as well as our daughter."

When examining responses to the open-ended questions, parents reported the following when discussing the well sibling's need for informational support. The mother of one 8 year-old sibling wrote, "I think one of the most helpful things that nurses can do with the well children is regularly explain to them what is happening, what the equipment is, what the medicines do, etc. Although I could do this for my child, I think the nurses would do a better job and at the same time it makes my child feel included while I'm paying attention to my son's doctor."

Another mother with two well children and a daughter with retinoblastoma reported, "My well children need to be reassured that they will not catch the same illness as my daughter. I heard there are books on cancer that are written for children. I think this kind of information would be helpful for my children but I don't know where to find them."

Parent Perceptions of Frequently Provided Interventions

The interventions reported by parents as most frequently provided are directed at meeting the emotional, appraisal, and informational needs of well siblings. As previously noted, these findings are consistent with sibling reports and the findings of Murray (1995) and Walker et al. (1992) who found emotional and informational support to be the most frequently provided social support interventions for well siblings and families of children with cancer. These findings suggest that nurses are consistently providing the same types of social support interventions in clinical practice. However, the interventions are only meeting the support needs of well siblings in part. There is a gap in providing interventions aimed at meeting the instrumental needs of well children. This study demonstrates the importance of determining what helps siblings adjust to having a sibling with childhood cancer by asking them what they perceive as most helpful. Historically, health care professionals working with families of children with cancer have implemented interventions aimed at providing support based on their perceptions of what is helpful. The current study underscores the importance of

ascertaining, from the perspective of the individual requiring the support, what is most beneficial.

Further t-tests examining well sibling and parent NSSSQ scores utilizing support subscales established there was one statistically significant difference on the NSSSQ Helpfulness Scale. Well siblings scored higher on the instrumental support subscale demonstrating the value well siblings place on this type of support when adjusting to having a brother or sister with cancer.

Based on the additional findings, it was evident that programs to provide support might be beneficial to well siblings. The statistical analyses exploring the differences between well siblings who did and did not receive support during the past year and scores on the emotional, informational, instrumental, and appraisal subscales of the NSSSQ helpfulness and frequency scales established there was a statistically significant difference on the emotional support subscale of the frequency scale of the NSSSQ. Siblings attending summer camp for well siblings scored higher on the emotional support subscale. With further analyses using one-tailed significance tests, the informational, instrumental, and appraisal subscales emerged as statistically significant. It is unclear whether this is a short-term effect. Siblings receiving support by attending the summer camp participated in the study within 4 weeks of attending camp.

The higher score on the emotional support subscale for siblings attending summer camp was not surprising to this researcher. During support groups for

well siblings, it was apparent that they felt acknowledged. For many siblings this recognition is missing in their lives as the focus of the disease process is on the child with cancer. Parents have repeatedly reported to the researcher that following support groups for well siblings, parents notice an improvement in the well child's overall level of happiness. For this reason, parents frequently request that support groups be offered on a regular basis.

Summary

Research findings from this study demonstrate that well siblings and parents agree more closely on what interventions are provided than what would be helpful for the well children. Well siblings are not being provided with all the types of support that they perceive to be most helpful. Furthermore, social support interventions currently being provided are directed at meeting well siblings' support needs in part only. Current interventions appear to be directed at meeting the well sibling's need for emotional support, but not instrumental support.

Predictors of Helpful Interventions

To date, there is a scarcity of research examining variables that may predict well sibling adjustment difficulties during the childhood cancer experience. The present study demonstrated no statistically significant relationship between any of the predictor variables (sibling age, sibling gender, number of months since diagnosis, and PAIC scores) when simple regression analyses were performed. However, multiple regression analyses demonstrated

sibling gender and PAIC scores emerging as significant predictors of NSSSQ total helpfulness score.

Significant predictors of sibling adjustment identified in another research study included parent depression, marital adjustment, annual family income, neighborhood/community social support, parent-sibling communication about the illness, and time since diagnosis (Cohen, 1985). The author found that as time since diagnosis increased, adjustment difficulties in well siblings decreased.

In a study using logistic regression analysis, Sloper and While (1996) found adjustment difficulties were related to the degree of disruption of family life occasioned by the illness and the siblings' perceptions of negative interpersonal effects on their lives. Well siblings whose mothers spent more nights at the hospital with the child with cancer had more adjustment difficulties than those siblings whose mothers had fewer overnight hospital stays. In addition, well siblings that were satisfied with the amount of support (e.g. day to day contact) they received from parents, had fewer adjustment difficulties (Sloper & While, 1996).

Finally, in a study investigating the long-term effects of the childhood cancer experience on well siblings, Van Dongen-Melman et al. (1995) found the effect of demographic, family, and disease-related variables on the siblings' psychosocial adjustment to be quite limited. For well siblings, predictors of psychosocial adjustment difficulties were gender and age of the sibling at the time

of diagnosis. Male siblings had more somatic complaints (e.g. headaches, abdominal discomfort) than females. Siblings who were older than 4 years of age at the time of diagnosis had greater difficulties with school performance than siblings who were younger (less than 4 years of age) when the child with cancer was diagnosed.

This research emphasizes the need to identify factors that would help predict sibling adjustment to the childhood cancer experience as well as identify those variables that place siblings at increased risk. The paucity of research in this area indicates the need to examine additional variables that may predict well sibling adjustment difficulties and enable health care professionals to identify strategies to enhance coping. With an improved understanding of what variables may predict sibling adjustment, it is hoped that support programs can prevent, or at the very least minimize, adjustment difficulties seen in children who have a brother or sister with cancer.

Recommendations

Recommendations for Future Use of the Nurse-Sibling Social Support

Questionnaire. This study further tested two instruments to measure social support for siblings of children with cancer. Specifically, the two instruments measured the siblings' and parents' perception of what social support interventions help well siblings adjust to the childhood cancer experience and how frequently these interventions are made available to siblings. The Nurse - Sibling Social Support

Questionnaire consists of 30 items assessing sibling and parent perceptions of supportive interventions. Based on House's (1981) conceptualization of social support, the instrument includes items measuring the emotional, instrumental, informational, and appraisal components of support.

Based on the psychometric properties, the NSSSQ is a useful instrument to assess what social support interventions school-age siblings of children with cancer perceive as being helpful and how frequently those interventions are made available to them by nurses working in clinical practice. The instrument also determines parental perceptions of interventions that are felt to be beneficial to well siblings. The instrument should be tested with larger, representative populations of siblings to establish norms and to more closely examine gender and ethnic differences. Research should also be conducted with school-age siblings of children with other childhood acute and chronic illnesses and long-term disabilities. Interventions aimed at providing social support could be implemented in clinical practice as a result of findings from these investigations.

Procedures used in developing the instrument, including the conceptual framework, generation of items based on the theoretical conceptualization, experiences of expert nurses and review of the literature, pilot testing with experts, parents and siblings, and the results of the present study provide strong support for the content validity of the instrument.

Further research is warranted to evaluate the psychometric properties of the NSSSQ. Because the psychometric properties were evaluated with a small sample, a limitation of this study is the small same size of the sibling and parent groups ($n = 50$ per group). Additional research is needed to examine how the instrument relates to other instruments measuring similar constructs. Prospective testing should include evaluation of both scales' validity by comparing the instruments with known reliable and valid scales. Determining correlations with other instruments besides the PAIC may provide support for construct validity. Furthermore, evidence for construct validity for the instrument can also be obtained from hypothesis testing. Using an adjustment to cancer index, it could be hypothesized that siblings who experienced more supportive interventions on a frequent basis would have better adjustment scores. The Children's Adjustment to Cancer Index was conceptualized from the literature that assesses school-age children's perceived lifestyle changes since the diagnosis of cancer (Hockenberry-Eaton, Manteuffel, & Bottomley, 1997). Additional work is essential to increase the sample size to provide satisfactory numbers for factor analysis. The factor analysis will provide support for the underlying construct of the instrument. With further refinement and development of these instruments, they will continue to be helpful measures to assess important issues for siblings of children with cancer experiencing adjustment difficulties.

The NSSSQ can be used as an instrument in descriptive, correlational, and experimental studies. It can also be used as an instrument to evaluate clinical practice by including it in ongoing nursing care evaluation studies. For example, an analysis of individual item scores on the NSSSQ might be helpful in identifying areas where nurses need to provide more supportive interventions to siblings of children with cancer based on what the siblings perceive to be helpful.

As survival rates for childhood cancer continue to increase, reliable and valid instruments to assess well sibling adjustment to the childhood cancer experience become more important. Instruments that assess the sibling's perception of supportive interventions in adjusting to the childhood cancer experience provide an insight that is unattainable by evaluating the parent's and health care professional's perception of the experience (Murray, in press c). These two instruments provide meaningful measures that will assist health care professionals in assessing the adjustment of well siblings to the childhood cancer experience.

Recommendations for Theory Development. During this research study it became obvious that most of the social support research and theory development has relied predominantly on adult-based social support theories. Research investigating the effects of social support on siblings of children with cancer is beginning (Murray, in press a). Consequently, social support issues particularly

for well siblings of children with cancer may not be sufficiently or thoroughly addressed (Murray, in press a; Woodgate, 1999b).

For health care professionals interested in the phenomenon of social support, there are additional challenges when the focus is on children. The two most important involve developmental differences and the availability of appropriate instruments that measure specific support needs for siblings of children with cancer (Murray, in press a, in press b, in press c; Woodgate, 1999b). It became readily apparent to the researcher that the need for health care practitioners to comprehend such issues is essential if they hope to actualize a more thorough understanding of social support in research and clinical practice for families of children with cancer.

Woodgate (1999b) reports that in order to establish a comprehensive knowledge base of social support in children, researchers must do more to ensure that social support theory is given the attention it deserves in the pediatric population. Continued research and theory development directed toward the study of social support with children would ensure that all dimensions of social support are given the mindfulness they merit. Researchers and clinicians must also develop a knowledge base that explains developmental differences in the types of social support experienced by children and adolescents who have a brother or sister who has cancer. This objective could be achieved by setting study inclusion criteria to include a wide age range, while ensuring that the sample size is large

enough to detect potential developmental differences (Woodgate, 1999). Studies should be representative of both younger as well as older siblings. However, other research methods (e.g., play, drawings) besides the use of instruments would need to be used with younger age groups (Murray, in press b). Furthermore, social support with respect to the different stages of childhood development would need to be considered in choosing self-report tools (Woodgate, 1999). Finally, incorporating theoretical underpinnings from the child development literature is appropriate throughout the theory building and research process.

Recommendations for Research. The previously cited review of the literature on siblings of children with cancer in Chapter 3 clearly shows that the childhood cancer experience is a stressor that may increase subjective feelings of stress by well siblings and in some cases lead to decreased psychosocial competencies and increased psychopathologies. Murray (1995; 1999a) cites that research on siblings with cancer has made some progress over the past few years but much more work needs to be done.

Although some research on the adaptation of siblings to the childhood cancer experience has focused on the positive effects of the illness experience on well siblings, most have taken on a deficit-perspective approach. Because positive outcomes have been elucidated, research efforts need to shift from a deficit-centered model to a more optimistic one that is focused on coping, adaptation, and resilience (Murray, 1999a). Researchers and clinicians need to focus not only on

the absence or presence of psychopathology and adjustment difficulties, but also on resilience to gain a more comprehensive understanding of the childhood cancer experience from the perspective of siblings (Woodgate, 1999a).

Research on the role of the sibling relationship in moderating the stressors associated with the childhood cancer experience, and in promoting sibling adaptation, should be studied further (Murray, 1995). Sibling relationships are powerful subsystem that could possibly be used to assist in a more positive adjustment. Previous researchers have pointed out that the special relationships that siblings share should be seriously taken into account when exploring interventions to be utilized with well siblings. The potential exists for siblings to be an extraordinary source of strength and consolation for each other (Rollins, 1990).

Research on sibling adaptation to the childhood cancer experience has underemphasized the role of social support as a moderator of illness-related effects on siblings' psychosocial adaptation (Murray, 1995). Types of social support that are relevant to sibling adjustment include emotional support, informational support, instrumental support (behaviors that directly help the person in need), and appraisal support (self-evaluation to interpret the meaning of a situation). Correlational research would be instrumental in determining the possible relationships between specific interventions aimed at providing different types of support and both short-term and long-term outcomes. Furthermore,

experimental studies would also be valuable to test the effectiveness of nursing interventions to assist in reducing adjustment difficulties and enhance coping in well siblings.

Other researchers have discussed the importance of future research directed at the benefit of using a control group including siblings of healthy children or a comparison group of well siblings of children with a childhood illness other than a pediatric malignancy (Wang & Martinson, 1996). The aim of this approach would be to ascertain whether the responses seen with siblings of children with cancer are unique to this population.

As a result of this study, the researcher believes that another area to consider would investigate sampling methods. Purposeful sampling of well siblings of children with various forms of cancer, siblings of children with recurrent disease, as well as participants from ethnically and culturally diverse backgrounds, would be contributive and allow for the transferability of findings across different cultures and disease processes (Murray, in press b; Wang & Martinson, 1996).

Studying the meaning of the childhood cancer experience for well siblings, and identifying interventions aimed at promoting adaptation, has just begun to occur (Murray, 1999a; Wang & Martinson, 1996). This study emphasizes the need for additional research that involves obtaining data directly from the most important source – the siblings. Future research should also focus

on younger and older sibling age groups, and should continue with a diverse population base from different socioeconomic, racial, and cultural backgrounds. Furthermore, both quantitative and qualitative studies are needed to fully address the childhood cancer experience for healthy siblings. Research methods framed within a qualitative methodology paradigm are particularly imperative. The researcher found the responses to the open-ended questions to be some of the most informative data. The qualitative perspective generated descriptively rich data that was not elicited by the questionnaire alone. Other researchers have found qualitative methods valuable in the study of social support due to the fact that social support is viewed to be an act of interpretation between support givers and support receivers (Jacobson, 1990; Woodgate, 1999b). Although there is quantitative and limited qualitative research in this area, continued use of qualitative methods will result in further generation of a rich description of events that will help to provide a foundation of information about important issues of social support in siblings of children with cancer and lead to theory building that is specific to children's social support processes.

Understanding the effects of the childhood cancer experience on siblings, and interventions aimed at moderating them, involves a complex matrix of variables that will only be fully comprehended with further research in the area of sibling adaptation. The findings of Murray (1995) suggest that effective interventions with siblings of children with cancer should be included in the

family centered approach to care. However, it is important to note that implementation of nursing interventions to provide social support to siblings should not be used on the basis of solitary studies. Rather, interventions should be evaluated and implemented based on findings which have been replicated clearly in the clinical research literature.

Recommendations for Clinical Practice. Although the diagnosis and treatment of childhood cancer has a significant impact on families, the literature distinctly demonstrates that this illness experience has an even greater effect on well siblings (Murray, 1999a). Cairns et al. (1979) points out that parents of children with cancer often times do not recognize that well siblings have concerns and fears. Siblings feel very isolated from their parents. Furthermore, some well siblings feel secluded from extended family members as well as their peer groups. Siblings perceive that the time, attention, and efforts of the parents are directed only toward the child with cancer with little attention to their needs (Cairns et al., 1979).

The findings of this study support that nurses working in the specialty of pediatric oncology nursing have an incredible opportunity to effect change in clinical practice that is directed at meeting not only the needs of the child with cancer and their parents, but also at meeting the well siblings' psychosocial needs. The literature distinctly shows that to date the psychosocial needs of well siblings have been overlooked in the process of providing comprehensive care to children

with pediatric malignancies (Murray, 1999a). Murray (1995) and Walker et al. (1992) have reported that one of the most clinically challenging tasks facing pediatric nurses in clinical practice today is finding ways to enhance well sibling adaptation during the efforts to attempt to achieve control over the childhood cancer disease process. Furthermore, as more is discovered about the effects of childhood cancer on the entire family system, pediatric nurses, practitioners, educators, and researchers are acquiring an increased cognizance that just as with the child with cancer, a far-reaching approach to sibling intervention is essential as well. Nurses working with children with cancer are in principal positions to help minimize and possibly prevent adjustment difficulties from becoming an unavoidable result of the childhood cancer experience in healthy siblings (Murray, 1995; Walker et al., 1992). This investigation emphasizes the need for nurses to decrease, and possibly prevent adjustment difficulties from occurring, by implementing social support interventions based on the perspective of what siblings believe help them adjust to the childhood cancer experience.

Pediatric nurses should use a number of intervention strategies that will be instrumental in facilitating sibling psychosocial adaptation to the illness experience. The initial step should be the completion of a comprehensive family assessment. This should include knowledge of what the siblings know about the illness, how much the parents want the well siblings to know, the number and ages of well siblings, the nature of the sibling relationships (i.e., birth order,

spacing between siblings, previous relationships), what types of social support resources are available, and how families have dealt with crisis situations in the past. Assessing these areas will be paramount in order to address the families' most imminent needs (Murray, 1993).

Results of this study show that early interventions with well siblings should include siblings in initial discussions of the childhood cancer experience. Previous researchers have reported that this procedure can have significant importance in facilitating the healthy sibling's adaptation (Cairns et al., 1979; Havermans & Eiser, 1994; Kramer, 1981). However, this should be done with the siblings' developmental stage in mind. Furthermore, assessment of how the parents are coping with the diagnosis will also be essential. If the parents are not able to accept the diagnosis, it may be difficult for them to also address the needs of the well child at this time (Kramer, 1981). Another critical finding of this study is that well siblings should be considered when developing the plan of care for the child with cancer. Involving siblings in this process has two very important advantages. First, it provides the pediatric nurse with direct access to the well sibling where an assessment of psychosocial adaptation and adjustment to the childhood cancer experience can be completed. Second, including the well sibling permits the sibling to offer information and their perspective on the circumstances surrounding the illness experience. Including the healthy sibling may reveal information that may have been overlooked by others (Kramer, 1981; Murray,

1993). Responses of siblings to the open-ended questions in this study certainly illustrate that because of their unique perspective, siblings have much to contribute to meeting the needs of the child with cancer, the parents, and themselves.

Siblings should be encouraged to visit the ill child in the hospital. This is another opportunity for clinicians to assess the adjustment of well siblings to the illness experience (Kramer, 1981; Murray, 1993). Previous researchers have identified this as an intervention that facilitates sibling adaptation (Kramer, 1981; Murray, 1995; Walker, 1988; Walker et al., 1992). This not only encourages sibling participation in the ill child's care, but it also nurtures the continuance of the sibling relationship between children (Harding, 1996; Kramer, 1981).

Well siblings should also become familiar with the hospital environment. Although considered to be an important intervention, other researchers have reported that siblings of children with cancer have been frightened by what they observed in the hospital setting (Havermans & Eiser, 1994). Havermans and Eiser (1994) support this intervention. However, they recommend that efforts be made by nurses to prepare siblings for hospital and clinic visits by orienting them to the hospital setting and special equipment (Havermans & Eiser, 1994).

Taking siblings on tours of the hospital environment is instrumental in helping to alleviate any misconceptions siblings have about what happens to their ill brother or sister during hospitalizations or clinic visits. This type of

intervention is critical for helping to meet the siblings need for appraisal support. Furthermore, during support groups, siblings frequently report this to be helpful and ask to go on additional tours at subsequent support group meetings.

This opportunity to tour the hospital setting provides a chance for the sibling to gain a sense of mastery over what happens to the child with cancer during hospitalizations. A supportive relationship between well siblings and hospital personnel is promoted as well. Nurses should ensure that siblings are provided with age-appropriate information about the disease, treatments, side effects, and prognosis if necessary. This information should make clear that the well sibling did not cause the illness and that the sibling will not catch the disease. It is important that siblings also be updated with age-appropriate disease-related information as changes in the ill child's condition occur. Siblings should be encouraged to ask questions and be provided with honest answers. Implementing these interventions in clinical practice will serve to meet the well siblings need for informational support. It is important to consider that when providing any information to well siblings, the parents should be consulted initially. Their wishes as to what is to be explained to their well children should be respected (Harding, 1996; Kramer, 1981; Murray, 1995; Snyder, 1986).

The researcher has found that initially siblings of children with cancer are reluctant to express their feelings. Previous researchers have reported this probably reflects the well siblings' insecurity about their uncertain position in the

family during the childhood cancer experience. They frequently fear that anything they say or do may make the situation even worse (Cairns et al., 1979; Wang & Martinson, 1996). Kramer (1981) purports that change in family roles and sibling responsibilities (i.e., increased expectations) give rise to the intensity of feelings felt by well siblings during the illness experience. The well child feels angry about parental overprotectiveness and overindulgence of the child with cancer as well as the disproportionate attention given to the ill child (Kramer, 1981).

Siblings need someone with whom they can express their feelings, concerns, and emotions. They need the opportunity to cry, to laugh, and to be happy. The siblings in this family crisis need to know that even though their parents spend more time with the ill child at the hospital, they are still loved and cared about despite what is happening in their family during the painful experience of childhood cancer (Harding, 1996; Murray, 1995, 1999a; Snyder, 1986). Siblings should be encouraged to express their feelings. They need an opportunity to share their feelings and emotions that develop as a result of the childhood cancer experience. Kramer (1981) found the most critical factor influencing sibling adjustment to the illness experience was the ability to openly communicate with parents and health care professionals. Previous research and clinical experience have suggested that open and truthful communication with well siblings minimizes feelings of jealousy, rejection, anger, fear, and acting-out behaviors (Kramer, 1981; Murray in press a). One of the few opportunities

siblings have to discuss their feelings openly, in an environment where they feel safe to do so, is a sibling support group. Being in a group with children with similar experiences validates that it is acceptable to candidly share feelings.

Sometimes pediatric nurses are in ideal positions to facilitate open communication and expression of feelings either by talking with the well siblings or encouraging parents to do so (Harding, 1996). Alaolmolki, Heinzer, Howard, and Marszal (1995) have identified one of the most important interventions for advanced practice nurses is to advocate to parents that siblings need to be reassured that they are cared about and appreciated. Cairns et al. (1979) report that one specific measure, that health care providers should use in order to facilitate the well siblings' healthy adaptation, is to include siblings in conferences with the health care team. According to Cairns et al. (1979), this intervention serves as an opportunity for health care providers to direct the parents' attention to the needs of the well siblings and make recommendation to parents to meet the sibling's psychosocial needs (Cairns et al., 1979).

The researcher believes that anticipatory guidance should be provided for parents to help identify potential areas of difficulties and sources of stress for siblings. Parents should be encouraged to explain the changes in the family system as a result of the illness experience. Well siblings need to understand that the changes in roles and responsibilities are temporary and will return to normal when the ill child is well (Harding, 1996). It should also be advocated that the

parents spend time with their well children. Because many parents have trouble reconciling the demands of the ill child versus the well child, assistance should be provided to parents to facilitate their ability to meet the psychosocial needs of all their children (Harding, 1996). These interventions will meet the well siblings need for emotional support.

Extended family members and/or community agencies can serve as helpful agents for providing instrumental support. Many siblings wish their lives could return to normal. It is important to keep life as close to normal as possible. As this study demonstrates, the well children should be encouraged to attend social activities, sporting events, and/or continue with hobbies. Support networks, such as family, friends and neighbors, are needed to help siblings continue with life as usual. Assistance, such as providing childcare and transportation to activities, can contribute to meeting sibling needs of instrumental support (Murray, in press a). Extended family members, family friends, and community agencies (i.e., schools, churches, social groups) should be educated about their potential role in helping to meet the needs of well siblings (Murray, 1993, 1998). Another mechanism that has potential to provide instrumental support is summer camp for well siblings. This experience would not only provide an opportunity for well siblings to spend time with children their own age, but also provide an occasion for emotional support.

Another very important recommendation for clinical practice is to determine what barriers exist to providing support to well siblings. The researcher's previous research has identified that pediatric oncology nurses report barriers to providing support to siblings (Murray, 1993; 1999b). Murray (1999b) reported that pediatric oncology nurses frequently reported staffing shortages, lack of access to siblings, institutional constraints, role boundary issues, and lack of support for sibling support groups as common barriers to meeting the needs of siblings. These findings suggest that additional consideration is needed to determine the best way to provide interventions for siblings given the barriers reported (Murray, 1999b).

Recommendations for Education. Results of this study illustrate that understanding the psychosocial needs of well siblings, in addition to the needs of the ill child and their parents, must be an integral part of delivering comprehensive family-centered care. Providing nursing care to children with cancer calls not only for a requirement of special knowledge and sensitivity to the ill child's needs, but those of the well sibling as well. Nursing programs should place greater emphasis on sibling responses to childhood illnesses. Students enrolled in all health related disciplines should have course topics that analyze the issues faced by healthy siblings when confronted with the illness experiences of childhood. Academic programs should make clear that, just as with the pediatric patient with cancer, a far-reaching approach to sibling intervention is necessary

and requires the psychosocial assessment of not only disease-related stressors, but non-disease stressors as well (Murray, 1995).

Nurses working at all levels of pediatric health care should be taxed to the fullest to utilize a wide variety of resources to provide lectures, seminars, and continuing education programs that address the unique needs of healthy siblings of children with a variety of childhood illnesses. These educational opportunities will provide the means for students in a variety of health care disciplines, and all health care professionals, to better comprehend what is involved in this very intricate pediatric health care experience (Murray, 1995).

Pediatric oncology nursing has long been recognized as one of the more complex and emotionally demanding challenges in nursing. Nurses in academia have an immense responsibility to educate nursing students, as well as nurses in clinical practice and research, to provide sensitive and comprehensive care to the entire family unit (Murray, 1993).

Self-Concept and Siblings of Children With Cancer

Additional findings of this study demonstrated that well siblings that received some type of social support over the past year had statistically significant higher scores on the PAIC self-concept scale and felt more supported emotionally. To date, there is a dearth of clinical research investigating self-concept as it relates to children with cancer, childhood cancer survivors, and siblings of children with cancer (South, 1995). In 1995, South found that school-age children

with leukemia, with lower levels of perceived social support, were more likely to have lower self-concept when compared to children with higher perceived support. The researcher also found a strong positive relationship between social support and self-concept of school age children with leukemia ($r = 0.545$, $p = 0.012$) (South, 1995). These findings were supported by an earlier study that reported self-concept as being significantly related to social support (Roberts, 1988). The findings of this dissertation study also suggest that social support may play an important function in sibling coping with the experience of childhood cancer.

In summary, if a relationship between social support and self-concept can be maintained, siblings of children with cancer at risk for adjustment difficulties could be identified and a foundation can be developed upon which to base nursing interventions to meet their psychosocial needs. Studies examining self-concept and social support may contribute empirical evidence for the evolution of interventions to prevent or minimize the incidence of adjustment difficulties (Varni et al., 1994). It is imperative that nurses working in pediatric oncology nursing have a reliable scientific foundation for anticipatory guidance and nursing interventions for possible difficulties with self-concept in siblings of children with cancer. Furthermore, an understanding of the relationship of social support, adjustment, and self-concept also warrants extensive understanding. The relationship between social support and self-concept must be sufficiently

established and fully comprehended in siblings of children with cancer so that adjustment difficulties can be prevented or at least be minimized.

Finally, a mechanism for assessing sibling adaptation to the childhood cancer and implementing interventions is needed. A conceptual model of social support for siblings of children with cancer is currently being developed by the researcher (Appendix J). Referrals to provide social support would come from parents who have noted changes in their well child's behavior, schools that have reported difficulties in academics/peer interactions, and health care organizations that may assess difficulties with the sibling adjusting to the childhood cancer experience. A multidimensional assessment is completed looking at who in the sibling's social network can meet the siblings' need for emotional, informational, instrumental, and appraisal support. In the next stage, planning begins to meet these identified needs. Consultation and collaboration among health care providers, parents, and the community is done in order to meet the perceived needs of the siblings. Following implementation of the interventions, aimed at providing social support, an outcome evaluation is accomplished. This cycle continues to repeat itself as the sibling deals with the stressors of the childhood cancer experience.

Conclusion

One of the principal goals of pediatric oncology research is the hope that the enhanced knowledge will lead to improvements in pediatric oncology nursing

clinical practice and help ensure an improved quality of life for children with cancer and their families. The results of this study demonstrate that well siblings of children with cancer perceive different types of support to be beneficial to their adjustment to the illness experience than their parents. Furthermore, this study also demonstrates that the perceptions of well siblings differ from what pediatric oncology nurses believe to help siblings as reported by Murray (1995).

The knowledge gained from social support research has the potential to facilitate pediatric oncology health care professionals in their assessment of the social support needs of well siblings. The same health care professionals must also recognize that sibling's perceptions of their own social support needs may not be congruent with those of their parents or the health care providers. This warrants the need for pediatric nurses to adopt a multiple perspective approach when assessing social support in siblings of children with cancer. When developing strategies for providing support for siblings, strategies must be grounded by comprehensive assessments. Embracing a comprehensive perspective will help pediatric nurses arduously address areas of concern so that interventions can be developed, tested in research, and implemented in clinical practice.

Generalizability of Findings. There are some issues specific to the current study which affect the interpretability of the results. Conclusions may not be generalized beyond the sample because a nonprobability purposive sample was

utilized and because of the sample size. The interpretation of the current findings is also somewhat limited by the sibling's age, ethnicity, and the family being associated with the military. A more diverse sample from different age groups, cultural backgrounds, and from the civilian community might demonstrate different findings.

Because the Nurse-Sibling Social Support Questionnaire (NSSSQ) is new, another issue is the validity and reliability. The fact that the measure relies solely on self-report complicates the question of its adequacy when one considers the possibility of the social desirability response factor. However, further development and use of this measure will lead to continued methodological and conceptual improvements over time.

The findings of this study suggest that effective social support interventions with siblings of children with cancer should be included in the family-centered approach to the care of the child with a pediatric malignancy. However, it is important to note once again that implementation of nursing interventions to provide support to well siblings should not be utilized on the basis of isolated studies. Rather, social support interventions should be assessed and implemented in clinical practice based on findings that have been replicated evidently in the scientific research literature (Murray, 1995). Additional research will help to increase health care professionals understanding of and ability to

minimize the incidence of adjustment difficulties and enhance sibling adjustment to the childhood cancer experience with an adaptive outcome.

Appendix A – An Explanatory Model of Adjustment Difficulties in Siblings of Children with Cancer

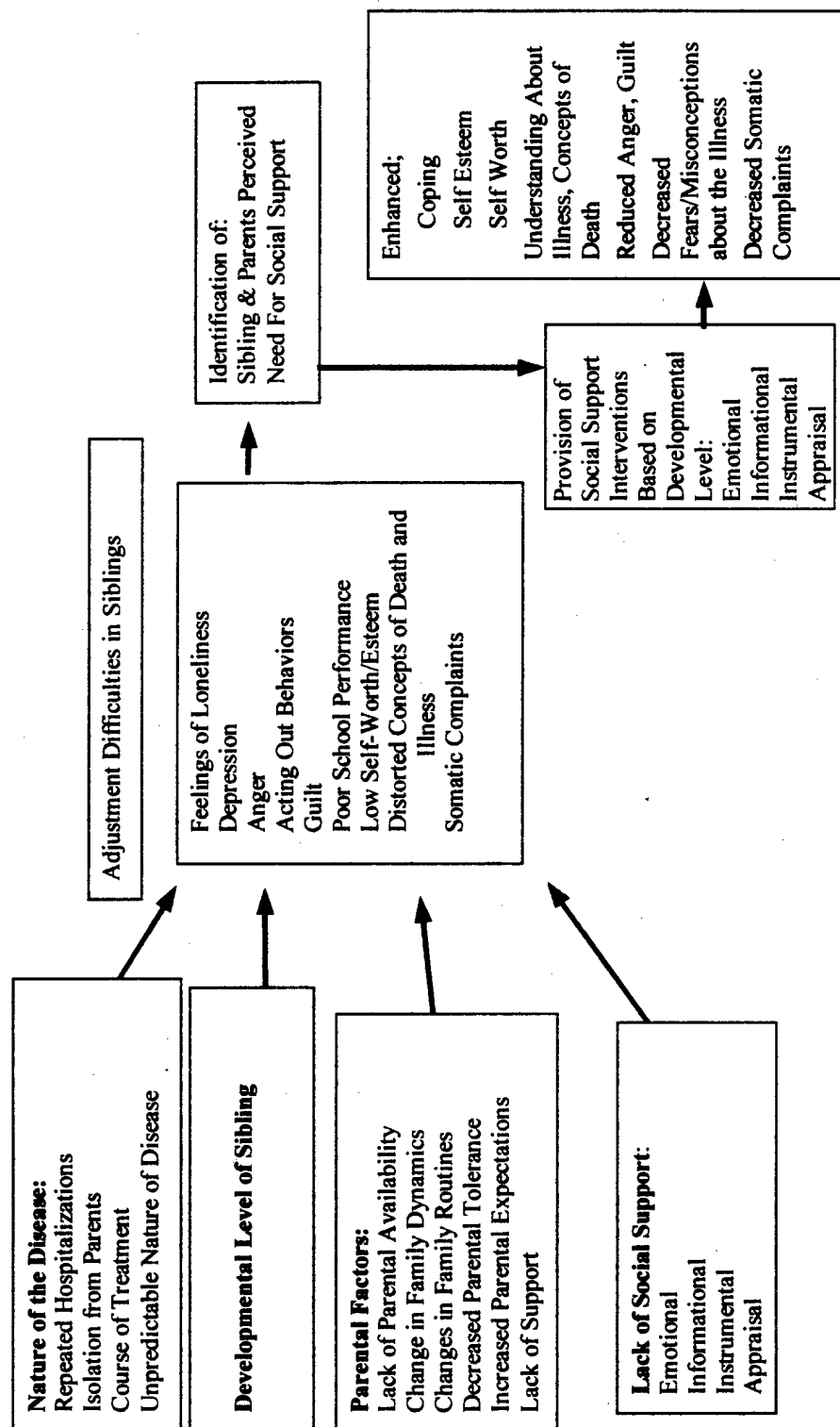


Figure 1: An explanatory model of adjustment difficulties in siblings of children with cancer.

Task	Calendar Month of Project					
	May	June-August	September	October	November	December

[illegible]

Appendix C – Letter of Invitation

Dear Parent,

I am very interested in learning about your child's views about their need for support or help during their brother's/sister's experience with childhood cancer. This study consists of a questionnaire that lists several ways nurses might be supportive or helpful to siblings of children with cancer. For example, "Allow me to visit my brother/sister in the hospital" is an item on the sibling questionnaire. The well sibling rates on a 5-point scale ranging from "Not Helpful (1) to Extremely Helpful (5)" how helpful this is to them. I am interested in knowing how important each item on the questionnaire is to them. In addition, I am interested in knowing how frequently these interventions are made available to them. This study will look at not only their perceptions of support, but yours as well. An example of an item on the parent questionnaire is "Teach my well child about cancer so he/she can understand what it is". You will be asked to rate on the same 5-point scale how helpful you think it is for nurses to do this for your well child. Finally, your child will be asked to complete a very short form that asks them to pick words that best describe them. The purpose of this form is to help me to test the questionnaire used for this study.

I invite you and your child to participate in this study so I can learn how to better help siblings of children with cancer in the future. You and your child's participation is voluntary and involves completing the questionnaire. All responses provided will be kept confidential. You and your child's confidentiality is protected as your names do not appear on the questionnaire. There are no known risks to participating in this study. You and your child's participation may be beneficial by providing a therapeutic opportunity for you both to express your thoughts and feelings about the childhood cancer experience. If you and your child choose to participate, your cooperation will be greatly appreciated.

If you have any questions or concerns, please feel free to contact me at (512) 795 - 9236.

Sincerely,

John S. Murray, Lt Colonel, USAF, NC
Pediatric Nurse Practitioner

Appendix D – Consent/Assent Forms

Parent Permission (Consent) Form

Study Title: Support for Siblings of Children with Cancer

Dear Parent,

The purpose of this study is to learn about your child's views about their need for support or help during their brother's/sister's experience with childhood cancer. This study will not only look at what they think is helpful, but what you think is helpful as well. A comparison will be made between both points of view. This letter is to ask for your permission to allow your child and yourself to take part in this research study. About 50 children and their parents will be in this study. Your name was selected from a computerized census list of pediatric oncology patients cared for at Wilford Hall Medical Center. This research study of Lieutenant Colonel John S. Murray, RNC, MS, CPNP, CS is for dissertation research. The researcher is a doctoral student at The University of Texas at Austin in the School of Nursing, and a certified pediatric nurse practitioner.

If you and your child agree to be in this study, you and your child will meet with the researcher to talk about the study. The researcher will answer any questions you and your child may have and if you and your child agree to participate in the study, he will ask you and your child to sign an agreement (assent) form. Confidentiality will be maintained by the use of coded questionnaires. There will be no identifying information on the forms so you and your child cannot be identified by name in any way. All of the permission and agreement forms are confidential and will be kept locked in a safety box for privacy. After permission is received from both you and your child, you and your child will be interviewed about support for well children during the childhood cancer experience. The questionnaire will take about 30 minutes to complete and filling out a general information sheet will take about 10 minutes. The study will be done by John Murray in the pediatric oncology clinic at Wilford Hall Medical Center clinic during summer vacation, weekends and/or holiday school breaks during the fall.

There are no known risks to participating in this study. Some parents and children may be uncomfortable sharing their feelings and concerns about certain questions with the researcher. If there is anything you or your child do not wish to discuss, then you and your child will not be asked anything further about that question. You and your child's participation may help you by providing an opportunity for you both to express your thoughts and feelings about the childhood cancer experience.

You and your child's decision to be in this study will not change your relationships with Wilford Hall Medical Center or The University of Texas at Austin, School of Nursing. If you and your child decide to be in this study, you can change your mind at any time and take yourself and your child out of the study without any consequences to you or your child. You and your child's participation will not change your health care privileges. You and your child will continue to receive medical care should you decide to discontinue participation in this study.

You are making a decision about letting yourself and your child be in this study. Your signature says that you have read the information in this permission form, have read it to your child, and you have decided that you and your child want to be in this study. If you and your child agree to be in this study, then we will ask you and your child to fill out an agreement form, which says that you and your child would like to be in this study. You and your child may ask to be removed from the study at any time and for any reason. You and your child can tell John Murray, the researcher, if you want to stop being in the study. You will be given a copy of this consent form to keep for your records.

If you have any questions, please feel free to call John Murray at (512) 795-9236. The supervisor of this study is Melanie Percy, Ph.D., RN, CPNP, a professor in pediatrics at The University of Texas at Austin, School of Nursing, (512) 471 - 7311.

Signature of Parent / Legal Guardian

Date:

Signature of Principal Investigator

Date:

If you want a copy of the group study findings, please initial here: _____

Principal Investigator:

Lieutenant Colonel John S. Murray, RNC, MS, CPNP, CS
7700 N. Capital of Texas Hwy
Apartment #1317
Austin, Texas 78731
(512) 795-9236
E-Mail: JMURRAY325@aol.com

Sibling Agreement (Assent) Form

Title of Study: Support for Siblings of Children with Cancer

I am being invited to take part in a study to look at my need for support or help during my brother's/sister's experience with childhood cancer. About 50 children and their parents will be in this study. This research study of Lieutenant Colonel John S. Murray, RNC, MS, CPNP, CS is for dissertation research. The researcher is a doctoral student at The University of Texas at Austin in the School of Nursing.

I understand that my mother/father/legal guardian has agreed to let me be in this study, and signed a permission (consent) form that says it is okay. If I agree to be in this study I will sign this agreement (assent) form. All of the forms I fill out are kept secret. If I agree to be in this study, I agree to be interviewed for this. I will be interviewed about support for brothers and sisters during the childhood cancer experience. The interview will take about 30 minutes and filling out a general information sheet about myself will take 10 minutes.

There are no known risks to being in this study. My taking part may be helpful by giving me a chance to express my thoughts and feelings about my brother or sister having cancer. I may not want to share some of my feelings and concerns about certain questions with the researcher. I understand that if there is anything I do not wish to discuss, then I will not be asked anything further about that question.

My decision to be in this study will not change my brother's/sister's care at Wilford Hall Medical Center or The University of Texas at Austin, School of Nursing. If I decide to be in this study, I can change my mind at any time and take myself out of the study by telling John Murray.

When I sign my name to this page, I am saying that this page was read by me and I want to be in this study. I will be given a copy of this form to keep.

Signature of Sibling

Date

Signature of Principal Investigator

Date

Principal Investigator:
Lieutenant Colonel John S. Murray, RNC, MS, CPNP, CS
7700 N. Capital of Texas Hwy
Apartment #1317
Austin, Texas 78731
(512) 795-9236
E-Mail: JMURRAY325@aol.com

Appendix E - Demographic Information Data Sheet – Sibling Version

1. Age of sibling _____
2. Position in family _____
3. Age of ill child _____
4. Sex of sibling Male ____ Female ____
5. Sex of ill child Male ____ Female ____
6. Diagnosis of ill child Leukemia ____ Lymphoma ____
 Brain Tumor ____ Bone Tumor ____
 Wilms Tumor ____ Rhabdomyosarcoma ____
 Retinoblastoma ____
 Other _____
7. Number of months since your brother's/sister's diagnosis _____
8. Treatment Phase Induction ____ Maintenance ____
9. Treatment of ill child (please pick all that apply)
 Chemotherapy ____ Radiation ____
 Surgery ____ Immunotherapy ____
 Bone Marrow Transplantation ____
 Other _____
10. Size of family (number of persons living in the household) _____
11. Marital status of parents Married ____ Separated ____ Divorced ____
12. Availability of parent surrogates (fill-in such as relative, neighbor) yes ____ no ____
13. Amount of time parent surrogates are available: Daily ____ Weekly ____ Monthly ____
14. If yes, relationship to sibling _____
15. Religion of family (please pick one) Catholic ____ Protestant ____ Other ____

16. Grade in School _____

17. What is your ethnic group?

___ African American ___ Hispanic

___ Non Hispanic/White ___ Native American

___ Asian ___ Other: (Please specify) _____

18. Did you go to a support group during the past year? yes _____ no _____

Appendix F - Demographic Information Data Sheet – Parent Version

1. Age _____
2. Are you the primary caretaker in the family Yes ___ No ___
3. Are you the Mother ___ Father ___
4. Age of ill child _____
5. Age of sibling _____
6. Sex of sibling Male ___ Female ___
7. Sex of ill child Male ___ Female ___
8. Diagnosis of ill child Leukemia ___ Lymphoma ___
 Brain Tumor ___ Bone Tumor ___
 Wilms Tumor ___ Rhabdomyosarcoma ___
 Retinoblastoma ___
 Other _____
9. Number of months since your child's diagnosis _____
10. Treatment Phase Induction ___ Maintenance ___
11. Treatment of ill child (please select all that apply)
 Chemotherapy ___ Radiation ___
 Surgery ___ Immunotherapy ___
 Bone Marrow Transplantation ___
 Other _____
12. Size of family (number of persons living in the household) _____
13. Marital status of parents Married ___ Separated ___ Divorced ___
14. Availability of parent surrogates (fill-in such as relative, neighbor) yes ___ no ___
15. Amount of time parent surrogates are available: Daily ___ Weekly ___ Monthly ___

16. If yes, relationship to parent _____

17. If yes, relationship to sibling _____

18. Religion of family? Catholic ___ Protestant ___ Other ___

19. How many years did you attend school?

___ 1 - 8 years

___ Graduated from Trade School or Community College

___ 9 - 11 years

___ Graduated from 4 year College

___ Graduated High School

___ Graduate School

20. What is your ethnic group?

___ African American

___ Hispanic

___ Non Hispanic/White

___ Native American

___ Asian

___ Other: (Please specify) _____

21. Combined Annual Family Income:

___ Less than \$20,000

___ \$20,000 - \$30,000

___ \$31,000 - \$45,000

___ More than \$45,000

22. Rank of Active Duty Parent: E1 ___ 01 ___ Other _____

E2 ___ 02 ___ Not Applicable ___

E3 ___ 03 ___

E4 ___ 04 ___

E5 ___ 05 ___

E6 ___ 06 ___

Appendix G - Nurse-Sibling Social Support Questionnaire – Sibling Version

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Listed below are ways nurses help children who have a brother or sister with cancer. For each question, first indicate **how helpful** you think each item is to you by circling the appropriate response. Then circle the response that best indicates **how often** nurses help you with this item.

	Helpfulness					Frequency				
	Not Helpful	Slightly Helpful	Helpful	Very Helpful	Extremely Helpful	Never	Seldom	Sometimes	Often	Always
1. Make sure the doctors/nurses include me when they plan how they are going to take care of my brother/sister	1	2	3	4	5	1	2	3	4	5
2. Include me in the first family conference at the time the doctors/nurses tell my parents my brother/sister has cancer	1	2	3	4	5	1	2	3	4	5
3. Include me in other family conferences they have to talk about my brother/sister	1	2	3	4	5	1	2	3	4	5

(Please continue on the next page)

	Not Helpful					Extremely Helpful				
	1	2	3	4	5	1	2	3	4	5
4. Allow me to visit my brother/sister in the hospital	1	2	3	4	5	1	2	3	4	5
5. Take me to see the pediatric/pediatric oncology unit	1	2	3	4	5	1	2	3	4	5
6. Teach me about cancer so I can understand what it is	1	2	3	4	5	1	2	3	4	5
7. Allow me to help with my brother's/sister's care	1	2	3	4	5	1	2	3	4	5
8. Tell me about changes in my brother's/sister's cancer	1	2	3	4	5	1	2	3	4	5
9. Give me more information as I learn and understand more about cancer	1	2	3	4	5	1	2	3	4	5
10. Tell me about things that might happen to my brother/sister (e.g., while receiving chemotherapy, during hospitalizations etc.)	1	2	3	4	5	1	2	3	4	5
11. Help me to find others that can help me deal with having a brother/sister with cancer (e.g., support networks/groups)	1	2	3	4	5	1	2	3	4	5
12. Help me to talk to my brother's/sister's doctors/nurses and other hospital staff	1	2	3	4	5	1	2	3	4	5

(Please continue on the next page)

	Not Helpful					Slightly Helpful					Very Helpful					Extremely Helpful					Never					Seldom					Sometimes					Often					Always				
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5										
13. Help me to talk about my feelings																																													
14. Help me to ask questions																																													
15. Give me honest responses to questions I ask																																													
16. Help my parents to notice my good behaviors (i.e. achievements in school, sports etc.)																																													
17. Help my parents to get me involved in hobbies, school activities																																													
18. Help me to attend support groups																																													
19. Help my parents with anticipatory guidance for potential areas of difficulty with my adjustment to the childhood cancer experience																																													
20. Encourage my parents to spend time with the other children in my family																																													
21. Provide assistance to my parents to help them meet the needs of the other children in our family																																													

(Please continue on the next page)

	Not Helpful					Slightly Helpful					Very Helpful					Extremely Helpful					Never					Seldom					Sometimes					Often					Always				
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
22. Teach community agencies (i.e. school, churches) about how they can help me with my brother's/sister's cancer	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
23. Help my parents to explain changes in the family system to me (i.e. changes in roles and responsibilities)	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
24. Help my parents to balance family life so that the focus is not always on my ill brother/sister	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
25. Talk about death and dying with me	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
26. Help me to understand that I did not cause my brother's/sister's illness	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
27. Help me to understand that I will not "catch" my brother's/sister's illness	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
28. Encourage my parents to discuss death with me	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
29. Give me books to help me better understand my brother's/sister's illness	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
30. Tell my parents about new information you find about how brothers/sisters behave when they have a brother/sister with cancer	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5

COMMENTS Sometimes it is difficult to say how you really feel by answering questions. I'm very interested in any comments you may have about this topic or questionnaire. Please use this section to talk about things you wish nurses would do to help children who have a brother or sister with cancer. Please tell me about things that nurses or your parents have done that have been helpful.

Thank you.

Appendix H - Nurse-Sibling Social Support Questionnaire – Parent Version

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Listed below are ways nurses help children who have a brother or sister with cancer. For each question, first indicate **how helpful** you think each item is to your child by circling the appropriate response. Then circle the response that best indicates **how often** you think nurses help your child with that item.

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1. Make sure the doctors/nurses include my child when they plan how they are going to take care of my child with cancer	1	2	3	4	5	1	2	3	4	5
2. Include my well child in the first family conference at the time they tell my spouse & I our child has cancer	1	2	3	4	5	1	2	3	4	5
3. Include my well child in other family conferences they have to talk about my child with cancer	1	2	3	4	5	1	2	3	4	5
4. Allow my well child to visit my child with cancer in the hospital	1	2	3	4	5	1	2	3	4	5
5. Take my well child to see the pediatric/pediatric oncology unit	1	2	3	4	5	1	2	3	4	5

Helpfulness

Frequency

Not Helpful
Slightly Helpful
Helpful
Very Helpful
Extremely Helpful

Never
Seldom
Sometimes
Often
Always

(Please continue on the next page)

	Not Helpful	Slightly Helpful	Helpful	Very Helpful	Extremely Helpful	Never	Seldom	Sometimes	Often	Always
	1	2	3	4	5	1	2	3	4	5
	1	2	3	4	5	1	2	3	4	5
6. Teach my well child about cancer so he/she can understand what it is	1	2	3	4	5	1	2	3	4	5
7. Allow my well child to help with my ill child's care	1	2	3	4	5	1	2	3	4	5
8. Tell my well child about changes in my ill child's cancer	1	2	3	4	5	1	2	3	4	5
9. Give my well child more information as he/she learns and understands more about cancer	1	2	3	4	5	1	2	3	4	5
10. Tell my well child about things that might happen to my ill child (e.g., while receiving chemotherapy, during hospitalizations etc.)	1	2	3	4	5	1	2	3	4	5
11. Help my well child to find others that can help him/her deal with having a brother/sister with cancer (e.g., support networks/groups)	1	2	3	4	5	1	2	3	4	5
12. Help my well child to talk to my ill child's doctors/nurses and other hospital staff	1	2	3	4	5	1	2	3	4	5
13. Help my well child to talk about his/her feelings	1	2	3	4	5	1	2	3	4	5
14. Help my well child to ask questions	1	2	3	4	5	1	2	3	4	5

(Please continue on the next page)

	Not Helpful					Extremely Helpful				
	1	2	3	4	5	1	2	3	4	5
15. Give my well child honest responses to questions asked	1	2	3	4	5	1	2	3	4	5
16. Help me to notice good behaviors in my well child (i.e. achievements in school, sports etc.)	1	2	3	4	5	1	2	3	4	5
17. Help me to get my well child involved in hobbies, school activities	1	2	3	4	5	1	2	3	4	5
18. Help my well child to attend support groups	1	2	3	4	5	1	2	3	4	5
19. Help me with anticipatory guidance for potential areas of difficulty with my well child's adjustment to the childhood cancer experience	1	2	3	4	5	1	2	3	4	5
20. Encourage me to spend time with the other children in my family	1	2	3	4	5	1	2	3	4	5
21. Provide me with assistance to help them meet the needs of the other children in our family	1	2	3	4	5	1	2	3	4	5
22. Teach community agencies (i.e. school, churches) about how they can help my well child with my ill child's cancer	1	2	3	4	5	1	2	3	4	5

(Please continue on the next page)

	Not Helpful					Extremely Helpful				
	1	2	3	4	5	1	2	3	4	5
23. Help me to explain changes in the family system to my well child (i.e. changes in roles and responsibilities)	1	2	3	4	5	1	2	3	4	5
24. Help me to balance family life so that the focus is not always on my child with cancer	1	2	3	4	5	1	2	3	4	5
25. Talk about death and dying with my well child	1	2	3	4	5	1	2	3	4	5
26. Help my well child to understand that he/she did not cause my child's illness	1	2	3	4	5	1	2	3	4	5
27. Help my well child to understand that he/she will not "catch" my child's illness	1	2	3	4	5	1	2	3	4	5
28. Encourage me to discuss death with my well child	1	2	3	4	5	1	2	3	4	5
29. Give my well child books to help him/her better understand my child's illness	1	2	3	4	5	1	2	3	4	5
30. Tell me about new information you find about how brothers/sisters behave when they have a brother/sister with cancer	1	2	3	4	5	1	2	3	4	5

(Please continue on the next page)

COMMENTS Sometimes it is difficult to say how you really feel by answering questions. I'm very interested in any comments you may have about this topic or questionnaire. Please use this section to talk about things you wish nurses would do to help children who have a brother or sister with cancer. Please tell me about things that you or nurses have done that have been helpful.

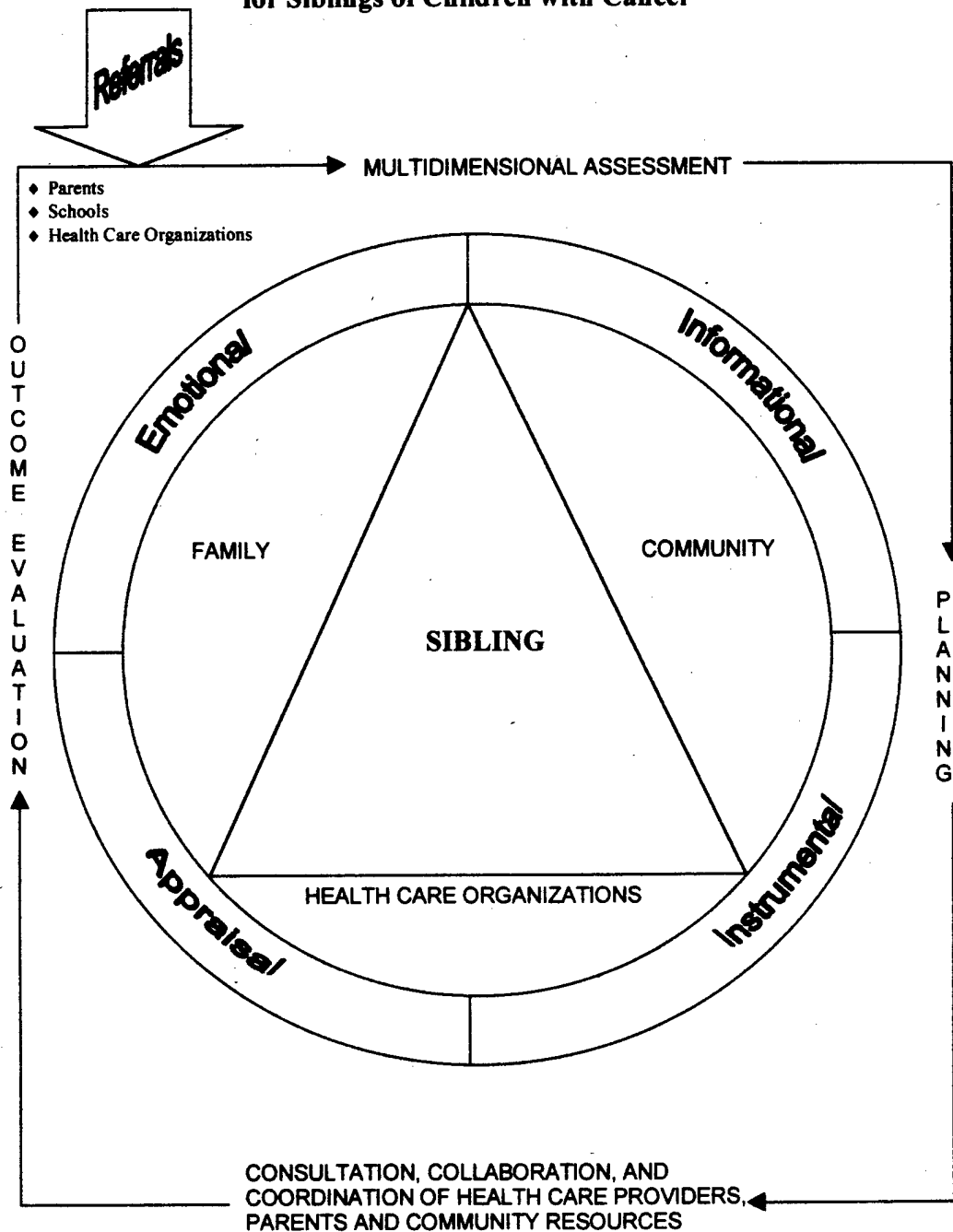
Thank you

Appendix I - Personal Attribute Inventory for Children

Directions: Please read this list of words. Put an X on the line beside the 15 words that best describe you.

- | | |
|--------------------------------------|-------------------------------------|
| <input type="checkbox"/> Afraid | <input type="checkbox"/> Happy |
| <input type="checkbox"/> Angry | <input type="checkbox"/> Healthy |
| <input type="checkbox"/> Awkward | <input type="checkbox"/> Helpful |
| <input type="checkbox"/> Bad | <input type="checkbox"/> Honest |
| <input type="checkbox"/> Beautiful | <input type="checkbox"/> Jolly |
| <input type="checkbox"/> Bitter | <input type="checkbox"/> Kind |
| <input type="checkbox"/> Brave | <input type="checkbox"/> Lazy |
| <input type="checkbox"/> Calm | <input type="checkbox"/> Lovely |
| <input type="checkbox"/> Careless | <input type="checkbox"/> Mean |
| <input type="checkbox"/> Cheerful | <input type="checkbox"/> Nagging |
| <input type="checkbox"/> Complaining | <input type="checkbox"/> Nice |
| <input type="checkbox"/> Cowardly | <input type="checkbox"/> Polite |
| <input type="checkbox"/> Cruel | <input type="checkbox"/> Pretty |
| <input type="checkbox"/> Dirty | <input type="checkbox"/> Rude |
| <input type="checkbox"/> Dumb | <input type="checkbox"/> Selfish |
| <input type="checkbox"/> Fairminded | <input type="checkbox"/> Show-Off |
| <input type="checkbox"/> Foolish | <input type="checkbox"/> Strong |
| <input type="checkbox"/> Friendly | <input type="checkbox"/> Sweet |
| <input type="checkbox"/> Gentle | <input type="checkbox"/> Ugly |
| <input type="checkbox"/> Gloomy | <input type="checkbox"/> Unfriendly |
| <input type="checkbox"/> Good | <input type="checkbox"/> Weak |
| <input type="checkbox"/> Great | <input type="checkbox"/> Wise |
| <input type="checkbox"/> Greedy | <input type="checkbox"/> Wonderful |
| <input type="checkbox"/> Handsome | <input type="checkbox"/> Wrongful |

Appendix J - Conceptual Model of Social Support for Siblings of Children with Cancer



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Vita

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